

ETHICAL OBJECTIONS TO LYING

Traditional religious and moral codes forbid lying. The Old Testament, for example, exhorts people not to bear false witness. Lying and deception also show disrespect for others. Those who are lied to or deceived generally feel betrayed or manipulated, even if the liar has benevolent motives. Lying also undermines social trust because listeners cannot be confident that other statements by the person will be truthful. This loss of trust is particularly grave in medicine because trust is essential in a doctor-patient relationship. In addition to undermining the speaker's integrity, lying is further condemned because a single lie often requires continued deception.

Lying and deception are considered *prima facie* wrong; the presumption is that they are inappropriate (1). Although some "white" lies may be accepted as customs that do not deceive anyone, lying generally requires a justification.

The ethical issue is whether general prohibitions on lying also apply to deception and nondisclosure in situations like Case 6.1.

DECEPTION OR NONDISCLOSURE TO THE PATIENT

Traditional codes of medical ethics did not require physicians to be truthful or forthcoming to patients (2). The writings of Hippocrates urge physicians to conceal "most things from the patient while you are attending him." Until recently, many physicians in the United States either did not tell patients about serious diagnoses such as cancer or deceived them (3). There are several reasons for such deception or nondisclosure.

REASONS FOR DECEPTION OR NONDISCLOSURE

Deception and Nondisclosure Prevent Serious Harm to Patients

Physicians might fear that disclosing a serious diagnosis might cause a patient to lose hope, refuse medically beneficial treatment, or become depressed. Few patients, however, refuse recommended treatment after learning a serious diagnosis (4). Although sadness and anxiety might be common, major depression or suicide attempts are rare. Some patients, however, currently have major depression or have attempted suicide previously. In such cases it would be justified to withhold the diagnosis while obtaining psychiatric consultation and assessing the likelihood of harm. In exceptional cases the risk of harm might be so serious that it would be justified to withhold the diagnosis until the patient's mental health improves.

Disclosure Is Not Culturally Appropriate

In many cultures patients traditionally are not told of a diagnosis of cancer or other serious illness. According to one study, although 87% of European-American patients and 89% of African-American patients want to be told if they have cancer, 65% of Mexican-Americans and 47% of Korean-Americans would not want to be told (5). Another study found that although 69% of European-American patients and 63% of African-American patients want to be told a terminal prognosis, only 48% of Mexican-Americans and 35% of Korean-Americans do. In some cultures disclosure of a grave diagnosis is believed to cause patients to suffer but withholding information gives serenity, security, and hope (6). Being direct and explicit might be considered insensitive and cruel. Families and physicians might try to protect the patient by taking on decision-making responsibility (7). Although it would be unfair to impose American standards of disclosure on patients who adhere to a different cultural standard, the crucial ethical issue is whether a patient wants to know the diagnosis, not what most people in their culture would want.

Patients Do Not Want to Be Told

If patients do not want to know their diagnoses, it would be autocratic to force them to receive information against their will, even in the name of promoting informed decisions. Indeed, it would violate patient autonomy to do so.

Disclosure Mig

In some cases th

CASE 6.2 Physi

On a routine che
cologist is a devc

Some physic
as contraceptive
transmission, su
scribe or recom
plicit with an im

REASONS AG

Most Patients I

The vast majorit
one survey, 94%
condition, "even
The desire to be
patients want rad
than waiting for t
tures in which no

Patients Need A

For patients to n
Chapter 3). It is
acceptable. Unde
tion without patie
affirmative duty t
sonally recommen

Physicians are
beliefs or their co
mutually acceptal
care without info
not be able to ma
with respecting th

Disclosure Has A

Disclosure of the
treatment regimen
serious diagnosis
might imagine the
illnesses are expla

Deception and A

Deception and no
not told the diagn
treatments.

Deception and A

In the long run it
house officer, or a
noses, they genera
patient the diagno

For example, exhorting people to be honest. Those who are motivated by benevolent motives. Other statements by physicians because trust is essential to a doctor's integrity, lying is that they are incapable of not deceiving anyone, deception and nondisclosure.

It is not forthcoming to patients from the patient. States either did not or are several reasons.

It is to lose hope, refuse recommended treatment might be common, currently have major difficulty to withhold the treatment of harm. In exceptional cases withhold the diagnosis.

For other serious illnesses, patients and 89% of African-Americans and Caucasians found that although patients want to be told a diagnosis, African-Americans do. It is to suffer but without explicit might be to let the patient by taking the opposite American standard, the crucial ethical principle in their culture.

Force them to receive information. Indeed, it would

Disclosure Might Violate the Physician's Conscience

In some cases there might be additional, physician-centered reasons for nondisclosure.

CASE 6.2 Physician objection to disclosure.

On a routine check-up, a 25-year-old married woman asks about options for contraception. The gynecologist is a devout Catholic whose religious beliefs oppose contraception and abortion.

Some physicians might have personal moral objections to specific medical interventions, such as contraception, abortion, or some measures to reduce human immunodeficiency virus (HIV) transmission, such as condoms and needle exchange. As a matter of conscience, they do not prescribe or recommend these interventions. Moreover, they might believe that they would be complicit with an immoral action if they even discuss these options with patients.

REASONS AGAINST DECEPTION AND NONDISCLOSURE

Most Patients Want to Know Their Diagnosis and Options for Care

The vast majority of patients in the United States want to know if they have a serious diagnosis. In one survey, 94% of those asked said that they "would want to know everything" about their medical condition, "even if it is unfavorable (8)." Ninety-six percent wanted to know a diagnosis of cancer. The desire to be told a serious diagnosis is so strong in the United States that more than 90% of patients want radiologists to tell them of abnormal results at the time of the imaging study rather than waiting for their primary physician to give them the results (9). Even among patients from cultures in which nondisclosure is traditional, many want to be informed of their diagnosis (5).

Patients Need Information for Decisions

For patients to make informed decisions, physicians need to disclose pertinent information (see Chapter 3). It is problematical if physicians fail to inform patients of options that are medically acceptable. Under the doctrine of informed consent, doctors are expected to disclose such information without patients having to ask for it. In other clinical settings, physicians have a role-specific affirmative duty to disclose all medically appropriate options to patients, even if they would not personally recommend them, without patients' having to ask (see Chapter 3).

Physicians are not obligated to carry out actions that would violate their fundamental moral beliefs or their conscience. They are free to withdraw from the care of a patient as a last resort if a mutually acceptable plan cannot be negotiated. However, it is problematical if physicians provide care without informing patients of options that are medically acceptable because patients would not be able to make informed choices. Thus, respecting the physician's conscience might conflict with respecting the patient's autonomy.

Disclosure Has More Beneficial than Harmful Consequences

Disclosure of the diagnosis and prognosis can benefit patients. Patients are more likely to adhere to treatment regimens that they understand and have agreed to. Furthermore, many patients with a serious diagnosis already suspect it. If physicians and family members remain silent, patients might imagine that the situation is worse than it actually is. Patients often feel relieved when their illnesses are explained and they can focus on treatment options.

Deception and Nondisclosure Require More Deception

Deception and nondisclosure usually require additional, more elaborate deceptions. If a patient is not told the diagnosis of cancer, deception is needed to explain the reasons for surgery or other treatments.

Deception and Nondisclosure Might Be Impossible

In the long run it is usually unrealistic to keep patients from knowing their diagnoses. A nurse, house officer, or x-ray technician might disclose it. When patients belatedly find out their diagnoses, they generally feel angry and betrayed. Thus, the practical issue is not whether to tell the patient the diagnosis but rather how to tell the patient.

oses, without resort-

are in which serious
ask patients whether
t results, while other
t Do you want me to
ults, it might be too
the diagnosis. Sim-
here is no reason to

is whether this is the
not want to be told a
not to be told should

not telling your father
's feelings as the nat-
family how disclosure

cope. Physicians can
ts, offering empathy,
bad news to patients.

ould discuss plans for
not want to be told
patients if they have

learn a serious diag-
might inadvertently
sep patients from the

not the diagnosis with
and helps the patient

reach closure in life, little might be gained from making the prognosis explicit. Such cases illustrate that ethical values taken for granted in the United States are not the only basis for good medical care.

Responding to Conscientious Objection by Physicians

In caring for patients, physicians have role-specific responsibilities that might transcend their own personal views. As in any clinical situation, physicians need to respond to the patient's medical and emotional needs, inform the patient about alternatives for care, and promote informed decision-making. At a minimum, physicians should tell patients that there are options for care they will not discuss because of their own religious or moral beliefs but that other physicians are willing to discuss. For the sake of continuity of care, physicians should inform patients at the onset of their moral objections to these interventions. However, it is ethically problematic for physicians to use their role to impose their moral or religious views on patients.

Similar dilemmas arise when a health care organization, such as a Catholic hospital, does not provide family planning or abortion services (16). Although there are strong reasons to respect an institutional policy that is based on religious beliefs, it is also important to inform women who present for care or schedule appointments that certain options will not be provided at that institution.

Similar dilemmas arise when hospitals and third-party payers forbid individual physicians from providing information to patients about family planning or abortion, writing prescriptions, or referring patients to other organizations for such services (16). Individual physicians should have the scope to discuss and recommend interventions that in their judgment are medically appropriate. To restrict such communication on the basis of an organization's policies or religious mission is to impose its views on both patients and health care providers and to deny important information to patients. It is simplistic to believe that all patients who seek care at an institution share the moral beliefs that animate the institutional policy.

DECEPTION OR NONDISCLOSURE TO THIRD PARTIES

Patients who seek benefits, such as insurance coverage, disability, and excused absences from work, often need physicians to give information to third parties. Physicians might consider using deception to help them gain such benefits. Although such deception might be motivated by a desire to help the patient, it is ethically problematic. Throughout this section it is assumed that the patient has authorized disclosure to the third party.

REASONS FOR DECEPTION

Physicians might claim they are acting in the best interest of patients when using deception. In doing so, physicians might regard themselves as patient advocates, helping their patients gain medical and social benefits. In some situations the benefits of deception seem to outweigh the harms.

CASE 6.3 Insurance coverage.

A 42-year-old accountant presents with a 2-month history of lower back pain that has not responded to conservative therapy with rest, nonsteroidal antiinflammatory agents, and exercises. There are no neurological symptoms, and the physical examination is normal. His father had prostate cancer that presented as back pain, and he is concerned that he might have a serious disease causing his symptoms. The physician and patient agree that an MRI scan would reassure the patient. His health insurance policy requires preauthorization for MRI studies, which are usually authorized only if there are neurological findings or other findings suggesting a systemic disease. The physician considers putting on the requisition that he has numbness and weakness in his legs to facilitate approval of the study.

In one survey, 39% of physicians reported that during the past year they had exaggerated the severity of a patient's condition, changed a patient's billing diagnosis, or reported signs and symptoms the patient did not have in order to help the patient get needed care (17). Such deception is more common when physicians believe that it is unfair for the plan not to cover the intervention,

when they believe that the insurer's appeals process was unwieldy, and when the patient's condition is more serious (18). The physician might believe that obtaining a drug for the patient is redressing a wrong rather than breaking an ethical guideline.

In Case 6.3 the benefits of deception for the patient seem large and greater than the costs of other alternatives. The physician believes that he and the patient have arrived at a mutually acceptable plan of care that addresses his concerns. The rationale for this plan, however, might be difficult for a busy practitioner to explain to a bureaucrat applying a standardized list of indications for the test. In other situations the harms of deception might seem very small, as in the following case.

CASE 6.4 Excuse from work.

A patient asks a physician to sign a form excusing an absence from work. He says that he had a severe upper respiratory infection but has now recovered. The physician did not see the patient while he was ill.

In Case 6.4 the physician might sign the form, even though the physician does not know whether the patient was actually sick or not. The doctor might consider the harm—inappropriate absenteeism—minor and better handled directly by the employer (19). It neither would be cost effective for patients to visit physicians for all self-limited illnesses that keep them from work nor would it be desirable to medicalize such conditions by encouraging patients to consult physicians. Even if the worker was not sick, perhaps he had a good reason to stay home—to care for a sick child, for example. For these reasons, physicians commonly certify work absences even when they have not examined the patient during the illness.

REASONS NOT TO DECEIVE

Deception Undermines Trust in Physicians

Physicians dealing with a specific case might not appreciate the impact of a practice of deception in these situations. Lying and deception undermine social trust because people cannot trust that other statements are truthful. It is especially problematic for physicians to lie or intentionally deceive others because the relationship between doctors and patients and society depends on trust. If physicians are known to use deception in some situations to help patients, they might also use it in other situations for other purposes.

It might seem unfair for the insurance company to deny coverage for care that is beneficial or to require physicians to assume heavy bureaucratic burdens. In situations like Case 6.3, physicians report that if the appeals process is cumbersome, they are more likely to use deception—for example, stating that the patient has numbness and tingling in his legs. The physician might argue that this statement is literally true; most people have such symptoms at some time in their lives.

Third parties expect truthful information. Physicians have an obligation to avoid misrepresentation to patients because of the fiduciary nature of the doctor-patient relationship (see Chapter 4). Physicians have similar obligations to avoid deception to these third parties, but for different reasons. The relationship between physicians and third parties is contractual rather than fiduciary. In contracts both parties are required to avoid deception and deal fairly (20). Insurers commonly require physicians to affirm that the information provided is accurate and complete. In Case 6.3 insurers consider such deception to be fraud and might bring legal charges.

It is unrealistic to expect that such deception to third parties will not be discovered. Computers help insurers to identify questionable claims. Similarly, other physicians review applications for disability from Social Security and worker's compensation (21). Once misled, third parties will mistrust other information from physicians and might require additional documentation. Physicians, who already complain of bureaucratic intrusions on the practice of medicine, might then face additional paperwork.

The Harms of Deception Outweigh the Benefits

When indirect and long-term harms are taken into account, the overall harms of deception outweigh the benefits (22). Deception about a patient's condition indirectly harms other people. Giving disability parking cards makes it more difficult for persons who are truly disabled to park. Deceptive claims for disability or insurance coverage force the public, workers, and employers to pay higher taxes or insurance premiums.

TABLE

Resolving Dilemmas

Consider whether a
Deception might be
Exhaust other altern
Involve patients who

RESOLVING DILEMMAS

The following su
order to gain ben

Consider Whether
Physicians need t
the issue.

CASE 6.5 Cancel

*A healthy patient i
write a note saying*

In Case 6.5 the
financial penalty.
obligation to help

In other cases
food, clothing, an
gation to provide
entitled, but it is
social benefits for
system is unjust. d

Deception Might

The literal truth m
is intended to dece
prevents harm to t
work without havi
patient reports th
ethical dilemma be
visits simply to ob
the patient the sub

Exhaust Other Alternatives

Physicians can oft
have several option
or order cancer sc
blood test. Pursuin
alternatives gives p

Involve Patients Who

Physicians often be
fact, patients who
cians to use decept
that they feel caught

the patient's condition
patient is redressing

after than the costs of
at a mutually accept-
ever, might be diffi-
list of indications for
n the following case.

s that he had a severe
atient while he was ill.

cian does not know
harm—inappropriate
either would be cost
them from work nor
o consult physicians.
e—to care for a sick
nces even when they

practice of deception
ple cannot trust that
o lie or intentionally
ity depends on trust.
they might also use it

that is beneficial or to
Case 6.3, physicians
deception—for exam-
cian might argue that
e in their lives.

avoid misrepresenta-
ship (see Chapter 4).
but for different rea-
ther than fiduciary. In
Insurers commonly
complete. In Case 6.3

iscovered. Computers
view applications for
led, third parties will
ocumentation. Physi-
medicine, might then

ms of deception out-
ms other people. Giv-
ruly disabled to park.
ers, and employers to

TABLE 6-2

Resolving Dilemmas about Deception to Third Parties

Consider whether an important health benefit is at stake.
Deception might not be necessary.
Exhaust other alternatives.
Involve patients who request deception.

RESOLVING DILEMMAS ABOUT DECEPTION TO THIRD PARTIES

The following suggestions might help physicians deal with patients' requests to use deception in order to gain benefits (Table 6-2).

Consider Whether an Important Health Benefit Is at Stake

Physicians need to ask in what sense they are helping the patient. In some cases health care is not the issue.

CASE 6.5 Cancellation of travel plans.

A healthy patient who has bought a vacation tour wishes to change his plans. He asks his physician to write a note saying that he is ill so he can obtain a refund.

In Case 6.5 the patient simply wants to break a business deal with the travel agency and avoid a financial penalty. Although physicians have a duty to provide beneficial medical care, they have no obligation to help patients gain business advantages.

In other cases physicians might want to help patients receive disability payments to obtain food, clothing, and shelter. Such necessities are essential for good health. Physicians have an obligation to provide truthful information that will help patients get social benefits to which they are entitled, but it is not at all clear that physicians should use deception to help certain patients get social benefits for which they do not qualify. Even if physicians believe that the current social system is unjust, deception in selective cases seems an inadequate way to address this unfairness.

Deception Might Not Be Necessary

The literal truth might resolve the dilemma. The strategy of using the literal truth is unethical if it is intended to deceive. However, employing the literal truth is appropriate if it is not deceptive and prevents harm to the patient (23). In Case 6.4 the physician was asked to certify an absence from work without having examined the patient during the illness. Some physicians simply write, "The patient reports that he was sick and unable to work (19)." This statement, which is true, shifts the ethical dilemma back onto the patient and employer. Furthermore, this strategy obviates physician visits simply to obtain work excuses for self-limited illnesses. The physician should also explain to the patient the substance of his note and the reasons for it.

Exhaust Other Alternatives

Physicians can often benefit patients without using deception. In Case 6.3 the physician might have several options for reassuring the patient. The doctor could refer the patient to a neurologist or order cancer screening tests, such as a prostate-specific antigen (PSA) level or a stool occult blood test. Pursuing these alternatives requires the physician's time and effort, but exhausting these alternatives gives physicians a stronger ethical justification for using deception as a last resort.

Involve Patients Who Request Deception

Physicians often believe that they alone must decide how to respond to requests for deception. In fact, patients who make such requests have ethical responsibilities as well. If patients ask physicians to use deception on a disability application or an insurance bill, physicians can frankly say that they feel caught between two ethical duties—to help the patient and to be truthful. Physicians

can reflect the dilemma back to patients, saying, "If I mislead your insurer, how would my patients trust me not to mislead them in other situations?" Furthermore, the physician can point out the problems that will occur later if the insurer requests documentation.

DECEPTION WITH COLLEAGUES

Physicians and trainees might use deception with colleagues. In one study, 19% of residents reported that they would fabricate a result of a laboratory test they had not checked if they were likely to be "ridiculed and reprimanded" for not checking it (24). In another scenario, 8% of residents said they would lie about checking for occult blood in a patient with anemia and fatigue who had suffered a myocardial infarction as a result of occult bleeding. Furthermore, more than 40% of respondents reported that they had witnessed another resident lying to an attending physician or another resident during the past year.

Deception with other physicians is ethically troubling for several reasons. If a physician tells other physicians that a test result is normal, without actually checking the results, patients might be harmed. If in fact the patient's result was actually abnormal, needed treatment might be delayed or omitted. In addition, physicians need to trust information from other doctors. If a doctor gives false information about a patient, colleagues cannot rely on other information from that doctor. Duplicating work wastes time and causes frustration.

As discussed in more detail in Chapter 36, it is understandable that trainees want to have a good reputation and avoid criticism. However, using deception to bolster one's reputation cannot be condoned.

In summary, there are strong ethical reasons for physicians to avoid deception and nondisclosure with patients. In addition, physicians should avoid deception about the patient's condition to third parties who have a right to such information. Physicians should keep in mind how deception could undermine the doctor-patient relationship and should seek constructive ways to resolve such dilemmas.

APPENDIX: BREAKING BAD NEWS

Plan the conversation. When ordering the test, the physician should also plan how to communicate the results. Most patients prefer to hear bad news in person rather than by telephone. In the inpatient setting, it is important to determine who will talk to the patient: the house officer, the attending physician, or the consultant.

Provide a calm setting. The physician should hold the discussion in a quiet, private place, sit down, and have a colleague answer pages. Before going to see the patient, the doctor can take a few moments to become collected.

Warn the patient that bad news is coming. "Mr. Jones, I'm afraid I have some bad news. Do you feel like talking now?" Such a warning allows patients to prepare for what is coming. A few patients will say that they are not ready to hear bad news.

Avoid euphemisms and jargon. Say "cancer" rather than "tumor," "growth," or "malignancy," which patients are likely to misinterpret.

Allow the patient to react. The patient might respond with "stunned silence, anger, disbelief, acute distress, or guilt (10)." Many physicians are uncomfortable with silence and fill it by talking, often with confusing medical jargon. It is better to give patients time to absorb the information, sort out their reactions, or cry.

Keep the first discussion brief. Patients generally comprehend little else after hearing they have a serious diagnosis. Doctors need to recognize "the glazed look that means the patient is no longer listening (12)." Detailed information about tests and treatments can often wait for subsequent visits.

Elicit the patient's reactions and concerns. Otherwise, physicians might make incorrect inferences about how the patient is feeling. Open-ended questions are helpful. "Most people are overwhelmed in this situation. How are you feeling?"

Provide realistic hope. Physicians need to emphasize that they will provide the best care they can and that they will be with the patient. If effective treatments are available, this should be stressed.

Show your concern. A detached demeanor might be interpreted as lack of concern. Physicians can say that they are sorry, in the sense of communicating regret. It is often helpful to reflect the

patient's and patient on the show concern as "I know w healthy pers

Repeat th information i can allow the

Share unc cians usually omy, physi average prog than the mea address the p pain, and dyn

REFERENCE

1. Bok S. Sec
2. Reiser SJ. V
3. Novack DH 1979;241(9
4. Appelbaum
5. Blackhall L
6. Gordon DB cancer in Tu
7. Surbone A.
8. President's Making Hea
9. Schreiber M vey of patie
10. Fallowfield
11. Miranda J. I
12. Brewin TB.
13. Quill TE. T.
14. McLauchlar
15. Ptacek JT. E
16. Gallagher J. 52:65-68.
17. Wynia MK. JAMA 2000;
18. Werner RM. bursement r
19. Holleman W
20. Farnsworth I
21. Carey TS, F- worker's cor
22. Bok S. Lying
23. Nyberg D. T
24. Green MJ. F their colleag

ANNOTATE

1. Bok S. Lying Offers a com more serious
2. Blackhall LJ 820-825. Reports that grave progn
3. Surbone A. I Points out th ing informati

ow would my patients
ian can point out the

dy, 19% of residents
checked if they were
scenario, 8% of resi-
temia and fatigue who
ore, more than 40% of
attending physician or

ns. If a physician tells
ults, patients might be
nt might be delayed or
. If a doctor gives false
m that doctor. Dupli-

ns want to have a good
reputation cannot be

ception and nondisclo-
patient's condition to
n mind how deception
e ways to resolve such

how to communicate
by telephone. In the
the house officer, the

dict, private place, sit
the doctor can take a

me bad news. Do you
coming. A few patients

th," or "malignancy,"

ence, anger, disbelief,
e and fill it by talking,
bsorb the information,

her hearing they have a
patient is no longer list-
t for subsequent visits.
make incorrect infer-
Most people are over-

e the best care they can
his should be stressed.
of concern. Physicians
n helpful to reflect the

patient's underlying emotions. "This must be very hard for you." Gestures such as touching the patient on the forearm or hand might convey empathy more effectively than words. Another way to show concern is to help with immediate details, such as calling a family member. Expressions such as "I know what you're going through" might be counterproductive; the patient might feel that a healthy person could not imagine having a fatal diagnosis.

Repeat the discussion at subsequent visits to ensure that the patient has understood. Providing information is a process, not a single conversation. At each visit, asking how the patient is doing can allow the patient to raise issues.

Share uncertainty with the patient. When patients ask how much longer they have to live, physicians usually do not give straightforward responses (10). In the spirit of respecting patient autonomy, physicians need to give patients the best information possible. When physicians cite an average prognosis, they need to make clear that an individual might have a longer or shorter survival than the mean. In addition to answering questions about prognosis literally, physicians also need to address the patient's psychosocial concerns, such as fears of losing control, suffering unrelieved pain, and dying alone.

REFERENCES

1. Bok S. *Secrets*. New York: Pantheon Books, 1982.
2. Reiser SJ. Words as scalpels: transmitting evidence in the clinical dialogue. *Ann Intern Med* 1980;92:837-842.
3. Novack DH, Plumer, R, Smith, RL. Changes in physicians' attitudes toward telling the cancer patient. *JAMA* 1979;241(9):897-900.
4. Appelbaum PS, Roth LH. Patients who refuse treatment in medical hospitals. *JAMA* 1983;250:1296-1301.
5. Blackhall LJ, Murphy ST, Frank G. Ethnicity and attitudes toward patient autonomy. *JAMA* 1995;274:820-825.
6. Gordon DB, Paci E. Disclosure practices and cultural narratives: understanding concealment and silence around cancer in Tuscany, Italy. *Soc Sci Med* 1997;46:1433-1452.
7. Surbone A. Truth telling to the patient. *JAMA* 1992;268:1661-1662.
8. *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Making Health Care Decisions*. Washington, DC: U.S. Government Printing Office, 1982.
9. Schreiber MH, Leonard M, Rieniets CY. Disclosure of imaging findings to patients directly by radiologists: survey of patients' preferences. *Am J Roentgenol* 1995;165:467-469.
10. Fallowfield L. Giving sad and bad news. *Lancet* 1993;341:476-478.
11. Miranda J, Brody RV. Communicating bad news. *West J Med* 1992;156:83-85.
12. Brewin TB. Three ways of giving bad news. *Lancet* 1991;337:1207-1209.
13. Quill TE, Townsend P. Bad news: delivery, dialogue, and dilemma. *Arch Intern Med* 1991;151:463-470.
14. McLauchlan CAJ. Handling distressed relatives and breaking bad news. *Br Med J* 1990;301:1145-1149.
15. Ptacek JT, Eberhardt TL. Breaking bad news: a review of the literature. *JAMA* 1996;276:496-502.
16. Gallagher J. Religious freedom, reproductive health care, and hospital mergers. *J Am Med Womens Assoc* 1997; 52:65-68.
17. Wynia MK, Cummins DS, VanGeest JB. Should physicians manipulate reimbursement rules to benefit patients? *JAMA* 2000;284(11):1382-1383.
18. Werner RM, Alexander GC, Fagerlin A. The "Hassle Factor": What motivates physicians to manipulate reimbursement rules? *Arch Intern Med* 2002;162(10):1134-1139.
19. Holleman WL, Holleman MC. School and work release evaluations. *JAMA* 1988;260:3629-3634.
20. Farnsworth EA. *Contracts*, 2nd ed. Boston: Little, Brown and Company, 1990:249-272.
21. Carey TS, Hadler NM. The role of the primary physician in disability determination for Social Security and worker's compensation. *Ann Intern Med* 1986;104:706-710.
22. Bok S. *Lying: Moral Choices in Public and Private Life*. New York: Pantheon Books, 1978.
23. Nyberg D. *The Varnished Truth*. Chicago: University of Chicago Press, 1993.
24. Green MJ, Farber NJ, Ubel PA, et al. Lying to each other: when internal medicine residents use deception with their colleagues. *Arch Intern Med* 2000;160(15):2317-2323.

ANNOTATED BIBLIOGRAPHY

1. Bok S. *Lying: moral choices in public and private life*. New York: Pantheon Books, 1978.
Offers a comprehensive discussion of lies, stressing that people who are lied to feel betrayed and consider lying more serious than the liar does.
2. Blackhall LJ, Murphy ST, Frank G, et al. Ethnicity and attitudes toward patient autonomy. *JAMA* 1995;274: 820-825.
Reports that fewer Mexican-American and Korean-American patients want to be told a serious diagnosis or grave prognosis, compared to European-Americans and African-Americans.
3. Surbone A. Truth telling to the patient. *JAMA* 1992;268:1661-1662.
Points out that in most other cultures it is customary for families and physicians to shield patients from disturbing information about their diagnosis or prognosis.

Keeping Promises

Physicians, like all people, make promises and are sometimes tempted to break them. Once made, promises are generally regarded as binding. In retrospect, however, some promises might seem imprudent or mistaken. The following cases demonstrate that some promises can be kept only if important ethical guidelines are violated.

CASE 7.1 Promise not to tell the patient that she has cancer.

A 61-year-old Mexican American widow undergoes a needle aspiration of a breast mass. Her daughter and son ask the physician not to tell the patient if the mass is cancer because they fear that she would not be able to handle the bad news. They point out that it is not customary in Mexico to tell women of her age that they have cancer. After breast cancer is diagnosed, the physician refers the patient to a surgeon. The surgeon believes that patients need to be involved in decisions regarding mastectomy or lumpectomy. In addition, the patient asks a Spanish-speaking nurse, "Why do I need surgery? Do I have cancer?" The surgeon and nurse feel constrained by the primary physician's promise not to tell the patient her diagnosis.

CASE 7.2 Promise to schedule tests.

A 54-year-old man, a heavy smoker, is hospitalized for hemoptysis, weight loss, and angina pectoris. A chest x-ray shows a 2-cm proximal lung mass, with hilar adenopathy. A bronchoscopy is scheduled to obtain a biopsy. When the intern walks by his room, the patient shouts, "This is outrageous. I haven't had breakfast, I haven't had lunch. Now they say they don't know when the test will be done and that I might have to go through all this again tomorrow. If this is how the hospital is run, I'm leaving." The intern, eager to appease the patient and continue with his other work, promises the patient that the test will be done that afternoon. He tells the nurse to call the bronchoscopy suite to say that the procedure needs to be done that afternoon.

Making and keeping promises is ethically important because it reduces uncertainty and promotes trust. However, Case 7.1 illustrates that in some situations keeping promises might be problematic, and Case 7.2 shows that some promises might be ill-advised or unrealistic.

THE ETHICAL SIGNIFICANCE OF PROMISES

A promise is a commitment to act a certain way in the future, either to do something or to refrain from doing something. Promises generate expectations in others, who in turn modify their plans and actions on the assumption that promises will be kept (1). In everyday social interactions, people commonly make promises and expect others to keep the ones they make. Promises might be

exchanged for
deliver goods i

Keeping pr
ing the future
of "promise" i
important even
harmonious so
on others to ke

If promises resulting tangibles allow people to know when the other feel free to breathe detriment, but I

Promise-keeping is based on the fact that patients might be misled by physicians. In addition, promising, for example, physicians to be candid about diagnosis, is enhanced, and it

PROBLEMS 1

None of us was
moment, under
Foolish promise
a gratuitous bo
other person is
retracted promi

Clinical dilemmas
guidelines. In C
lates the guideli

In Case 7.2, would take place

SUGGESTION

DO NOT MAIL

A statement that the patient or family as a person is likely to. Patients are.

ADDRESS THE

If someone asks
ing concerns and
the concerns und
Case 7.2 the phy
and anger.

to break them. Once
the promises might
promises can be kept

it mass. Her daughter
y fear that she would
sico to tell women of
is the patient to a sur-
viving mastectomy or
ed surgery? Do I have
omise not to tell the

nd angina pectoris. A
scopy is scheduled to
outrageous. I haven't
will be done and that
run, I'm leaving." The
s the patient that the
to say that the proce-

uncertainty and pro-
mises might be prob-
lematic.

nothing or to refrain
n modify their plans
ial interactions, peo-
s. Promises might be

Keeping Promises

55

exchanged for other promises, as in a business contract. For example, a merchant might promise to deliver goods in exchange for the promise of payment on delivery.

Keeping promises is desirable for several reasons. It results in beneficial consequences by making the future more predictable, relieving anxiety, and promoting trust. Indeed, another definition of "promise" is "that which causes hope, expectation, or assurance (2)." Keeping promises is also important even if there are no short-term beneficial consequences. Promise-keeping is essential for harmonious social interactions. If promises are widely broken, people would be unwilling to rely on others to keep commitments.

If promises are broken, the person to whom the promise is made often suffers a setback (3). The resulting tangible harm might be inconvenience and monetary losses. Moreover, it seems unfair to allow people to break promises simply because it would be to their advantage to do so, particularly when the other person has relied on the promise. The very concept of promises is negated if people feel free to break them. It is manipulative to expect others to honor their promises, even to their detriment, but to break one's own promises when it is in one's self-interest (3).

Promise-keeping is especially important for physicians. Because the doctor-patient relationship is based on trust, patients often feel betrayed if physicians break promises. Once betrayed, patients might be less likely to trust the individual physician or the medical profession. Promises by physicians might help patients cope with the uncertainty and fears inherent in being sick. In addition, promises establish mutual expectations that benefit both physicians and patients. For example, physicians promise confidentiality of medical information; in return, patients are more candid about discussing sensitive issues pertaining to their health. Thus, the patient's well-being is enhanced, and the physician's work is facilitated.

PROBLEMS WITH KEEPING PROMISES

None of us want to keep all the promises we make. Some promises are made on the spur of the moment, under emotional stress, with inadequate information, or without proper deliberation (3). Foolish promises that put one at a great disadvantage are often retracted, particularly if they confer a gratuitous boon on the other person. People might excuse breaking such promises because the other person is no worse off than if the promise had never been made in the first place. With many retracted promises, the other person has taken no action in reliance on the promise.

Clinical dilemmas occur when keeping promises would require actions that violate other ethical guidelines. In Case 7.1 the surgeon and nurse believe the initial promise not to tell the patient violates the guideline of respecting patient autonomy.

In Case 7.2 the intern's promise was misleading because he could not guarantee that the test would take place that afternoon.

SUGGESTIONS FOR PHYSICIANS

DO NOT MAKE PROMISES LIGHTLY

A statement that the physician regards as kindly reassurance might be interpreted by the patient or family as a promise. Even if the physician does not think a promise is important, the patient is likely to. Patients typically are more upset when physicians break promises than the physicians are.

ADDRESS THE CONCERNS UNDERLYING THE REQUEST FOR A PROMISE

If someone asks the physician to make an unrealistic promise, the physician can elicit the underlying concerns and address them in other ways. Thus, in Case 7.1, the physician needs to understand the concerns underlying the family's request not to tell the patient her diagnosis (see Chapter 6). In Case 7.2 the physician needs to listen to and empathize with the patient's feelings of frustration and anger.

DO NOT PROMISE OUTCOMES THAT ARE OUT OF YOUR CONTROL

Physicians should avoid making promises that are beyond their control to keep. Because clinical outcomes are inherently uncertain, it is unrealistic to make a promise that guarantees a good outcome or the absence of complications after a procedure. Given the complex organization of modern medicine, it is misleading to make promises about the actions of other members of the health care team. After all, other physicians and nurses are autonomous agents who have free will and their own moral and professional values. Thus, in Case 7.1, even if the physician agrees not to disclose the diagnosis to the patient, another health care worker might disclose it. Furthermore, the physician should be clear that, if asked directly, she will tell the patient she has cancer.

In Case 7.2 physicians should not make promises about situations not under their direct control, such as the scheduling of bronchoscopy. In the short run it might seem easier to promise that the test will be done rather than to listen to the patient complain about problems. However, making a promise that might not be kept is likely to cause more problems in the long run. It might be better simply to listen and acknowledge that the patient has every right to be angry. Realistically, what the doctor can promise is to look into the matter and to do his or her best to make sure that such delays and inconvenience do not happen again. If the doctor makes such promises, the doctor needs to follow up on them appropriately—for instance, by calling the patient ombudsman or filing an incident report with the charge nurse.

DO NOT VIOLATE ETHICAL GUIDELINES BECAUSE OF AN ILL-CONSIDERED PROMISE

Although promise-keeping is important, it is not an absolute duty. Other ethical guidelines are also important and might take priority in some situations. In some cases breaking the promise might be the lesser of two evils. The strongest case for overriding the promise-keeping occurs when the following conditions are met:

- Keeping the promise would violate another important ethical guideline. In Case 7.1 keeping the promise would require deception by the physician and compromise the patient's autonomy.
- The countervailing ethical considerations were not taken into account when the promise was made.
- The clinical and ethical situation has changed significantly since the promise was made. In Case 7.1 the doctor promised not to tell the patient before she asked whether she had cancer.
- Someone else made the promise. Although a person's promise can bind his own future actions, that person has no authority to bind others, such as the surgeon in Case 7.1 or the consultant performing the bronchoscopy in Case 7.2.
- The promise was stated implicitly rather than explicitly.

In Case 7.1 respect for patient autonomy and avoiding deception should prevail over keeping a promise to third parties. It is usually better to admit that the promise was a mistake and to deal with the consequences as directly and compassionately as possible.

In summary, promises can allay patients' fears and uncertainty. It is important to keep promises because other people rely on them. Breaking promises undermines trust in the individual physician and in the medical profession, yet keeping promises is not an absolute ethical duty. Sometimes respecting a promise might require the physician to violate other important ethical guidelines. In exceptional situations breaking a promise might be justified as the lesser of two evils.

REFERENCES

1. Farnsworth EA. *Contracts*, 2nd ed. Boston: Little, Brown and Company, 1990:39–110.
2. *Webster's revised unabridged dictionary*, (<http://www.dictionary.com>).
3. Fuller LL, Eisenberg MA. *Basic contract law*, 4th ed. St. Paul: West Publishing Company, 1981:1–8.

OL

ap. Because clinical
trantees a good out-
rganization of mod-
mbers of the health
s have free will and
an agrees not to dis-
it. Furthermore, the
s cancer.
their direct control,
to promise that the
However, making a
n. It might be better
ealistically, what the
are that such delays
doctor needs to fol-
or filing an incident

d guidelines are also
be promise might be
occurs when the fol-

Case 7.1 keeping the
ent's autonomy.
e promise was made.
as made. In Case 7.1
ncer.
own future actions,
the consultant per-

avail over keeping a
take and to deal with

ant to keep promises
individual physician
cal duty. Sometimes
ethical guidelines. In
wo evils.

ny. 1981:1-8.

SECTION II

Shared Decision Making

An Approach to Decisions About Clinical Interventions

Medical interventions might allow accurate diagnosis and effective treatment, but they might also be applied when their benefit is questionable or when patients would not want them. Physicians therefore must try to avoid two types of errors: withholding potentially beneficial tests and therapies that the patient would want and imposing interventions that are not beneficial or not wanted.

This brief chapter presents an approach to decisions about clinical interventions. The general approach to ethical issues in Chapter 1 can be adapted to such decisions (Fig. 8-1). The key questions are as follows:

IS THE INTERVENTION FUTILE IN A STRICT SENSE?

Sound ethical judgments require accurate medical information. Physicians are under no obligation to provide interventions that are futile in a strict sense (*see* Chapter 9).

DOES THE PATIENT HAVE ADEQUATE DECISION-MAKING CAPACITY?

This is a crucial branch point in decision-making. Chapter 10 discusses how to determine whether a patient lacks decision-making capacity.

IF THE PATIENT IS COMPETENT, WHAT IS THE PATIENT'S INFORMED DECISION?

Competent, informed patients may refuse medical interventions (*see* Chapter 11). Patients frequently lack decision-making capacity when decisions about medical interventions must be made. If the patient lacks decision-making capacity, two additional questions need to be posed.

IF THE PATIENT IS NOT COMPETENT, HAS HE OR SHE GIVEN ADVANCE DIRECTIVES?

Clear and convincing advance directives should be respected (*see* Chapter 12). In the absence of such advance directives, decisions should be based on what the patient would want or what is in his or her best interests (*see* Chapter 12).

IF THE PATIENT HAS NOT CLEARLY INDICATED WHAT HE OR SHE WOULD WANT DONE IN THE SITUATION, WHO SHOULD SERVE AS SURROGATE?

Generally, the surrogate should be a person designated by the patient or a close family member (*see* Chapter 13).

This book then considers disagreements between doctors and patients over medical interventions. Chapter 14 analyzes insistence by patients or surrogates on interventions that physicians regard as inappropriate. Chapter 15 discusses conclusions about life-sustaining interventions that are commonly drawn but that prove misleading on closer analysis. Chapter 16 discusses how ethics committees or ethics consultants can help physicians resolve ethical dilemmas.

Next, this book analyzes life-sustaining interventions in specific situations. Chapter 17 discusses Do Not Resuscitate (DNR) orders. Often, discussions about DNR orders are the first step in

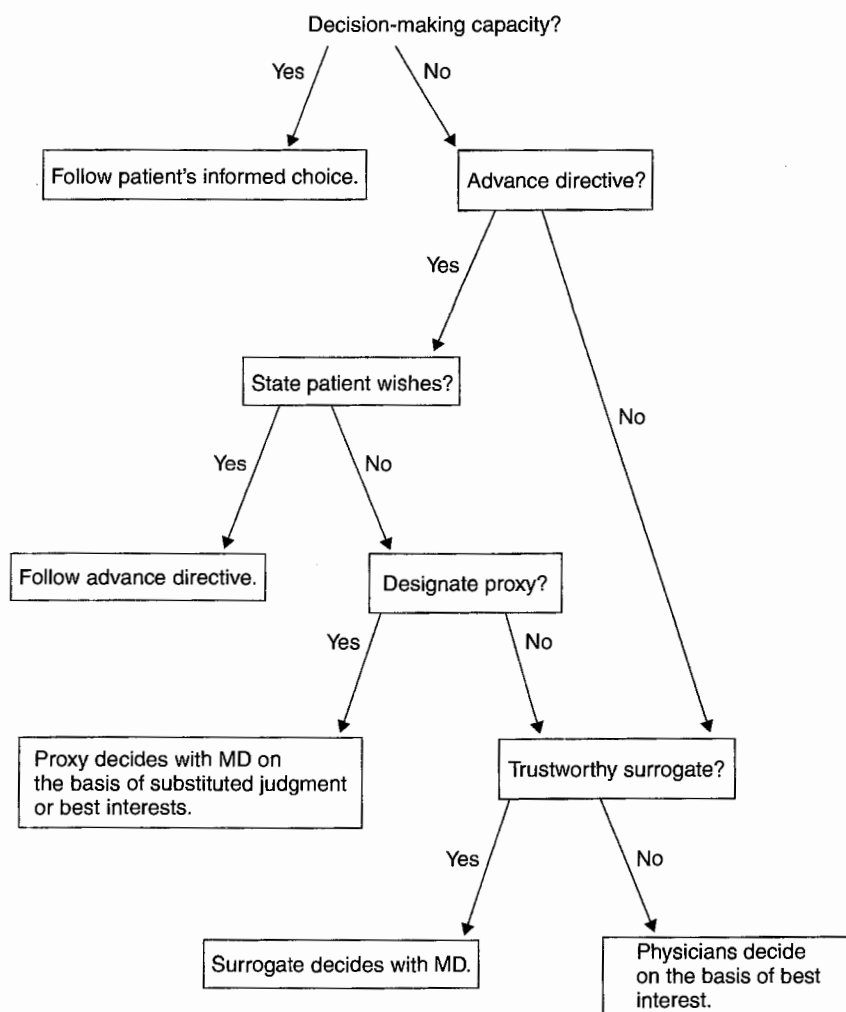


FIGURE 8-1 • Flow chart for clinical decisions.

a comprehensive evaluation of the goals and plans for care. Chapters 18-21 discuss physician-assisted suicide, tube feedings, the persistent vegetative state, and the determination of death.

Legal issues are then presented. Chapter 22 analyzes landmark legal cases that have dramatized dilemmas about life-sustaining interventions.

Patient autonomy is a central principle of medical ethics. The term "autonomy" is derived from the Greek word *autonomia*, which means "self-governance." In the medical context, it refers to a patient's right to make decisions about their own care without undue influence from others. Physicians are ethically obligated to respect their patients' autonomy, provided the patient has the capacity to make decisions and is acting voluntarily.

STRICT LIABILITY
Physicians can be held strictly liable for malpractice if they fail to meet the standard of care, regardless of whether they intended to cause harm or were negligent.

INTERVIEW

CASE 9.1
A 74-year-old woman with advanced dementia is being considered for a life-sustaining intervention. The physician is faced with a difficult decision regarding whether to proceed with the intervention.

In this case, the physician is faced with a difficult decision regarding whether to proceed with the intervention. The physician must consider the patient's best interests, the potential benefits and risks of the intervention, and the patient's autonomy.

CARDIAC HYPOTENSION

CASE 9.2
A woman is being considered for a life-sustaining intervention. The physician is faced with a difficult decision regarding whether to proceed with the intervention.

Futile Interventions

Patients or surrogates sometimes request medical interventions that physicians consider irrational or pointless. The concept of futility seems an appealing way to resolve such disagreements. The term “futility” comes from a Latin word meaning “leaky (1).” In classical mythology the gods condemned the daughters of Danaus to carry water in leaky buckets (1). No matter how hard they tried, they could never achieve their goal of transporting water. By analogy, futile medical interventions would serve no meaningful purpose, no matter how often they are repeated.

Physicians claim that judgment of futility is a matter of professional expertise. In this view physicians may decide unilaterally to forego futile interventions rather than share with patients or surrogates. Because the term futility gives decision-making power to physicians, however, it must be used with caution. The term is fraught with confusion, inconsistency, and controversy.

STRICT DEFINITIONS OF FUTILITY

Physicians use the term in different ways (2–5). In three strictly defined senses, medical futility justifies unilateral decisions by physicians to withhold or withdraw interventions (Table 9-1).

INTERVENTION HAS NO PATHOPHYSIOLOGIC RATIONALE

CASE 9.1 Antibiotics not active against organism.

A 74-year-old woman has progressive septic shock with Staphylococcus infection despite treatment with appropriate antibiotics. The patient’s family requests an antibiotic that they learned about on the Internet. The antibiotic is active only against gram-negative bacteria.

In this case there is no pathophysiological rationale for the antibiotic because it is not effective against the gram-positive bacteria causing this patient’s illness. The antibiotic would provide no physiological benefit by raising the patient’s blood pressure. Even if the family insists on the drug, there is no medical reason to administer it.

CARDIAC ARREST OCCURS BECAUSE OF REFRACTORY HYPOTENSION OR HYPOXEMIA

CASE 9.2 Patient with progressive septic shock.

A woman is comatose, on renal dialysis, and on a ventilator. On increasing doses of vasopressors, her mean arterial pressure falls to 60 mmHg. Her physicians want to write an order not to resuscitate in case of a cardiopulmonary arrest.

side
of best

discuss physician-
ation of death.
not have dramatized

TABLE 9-1**When Is an Intervention Futile in a Strict Sense?**

Intervention has no pathophysiologic rationale.

Cardiac arrest occurs because of refractory hypotension or hypoxemia.

The intervention has already failed in the patient.

In Case 9.2 cardiopulmonary arrest occurs because of progressive hypotension despite maximal support of the patient's circulation and oxygenation. Effective circulation cannot be sustained in this patient despite appropriate therapy. If her hypotension results in cardiopulmonary arrest, cardiopulmonary resuscitation (CPR) could not restore effective circulation. Even if cardiac rhythm were restored, she would again have refractory hypotension, which would again result in cardiopulmonary arrest.

THE INTERVENTION HAS ALREADY FAILED IN THE PATIENT**CASE 9.3 No response to CPR.**

A 54-year-old man suffers a cardiac arrest in the emergency room. CPR and advanced cardiac support are initiated promptly. After 30 minutes all measures recommended in the American Heart Association guidelines have been attempted. He remains in asystole. His family insists that resuscitation be continued.

An adequate clinical attempt of CPR has failed to achieve the fundamental goal of restoring effective circulation and breathing. It is pointless to continue or repeat interventions that have already failed.

These three strict senses of "futility" are as plain as the root metaphor of carrying water in leaky buckets. A miraculous recovery might occur if such a futile intervention is attempted, but clinical decisions should not be based on the possibility of miracles. The determination that an intervention is futile in these strict senses is based on objective data or judgments within the expertise of physicians. Physicians have no ethical duty to provide interventions that are futile in these strict senses; indeed, they generally have an ethical obligation *not* to provide them.

LOOSE DEFINITIONS OF FUTILITY

The term "futility" is also used in several looser senses that are confusing, involve value judgments, and do not justify unilateral decisions by physicians to withhold interventions (4–6). Sometimes the phrase "not medically indicated" is used in similar ways.

CASE 9.4 Recurrent aspiration pneumonia and severe dementia.

A 74-year-old man with severe dementia is hospitalized for the third time in 6 months for aspiration pneumonia. At baseline he sometimes recognizes his daughter and smiles when watching television or listening to music. The daughter, his only surviving relative, insists that he be treated with antibiotics. The resident exclaims, "Treating him is futile! His dementia is not going to improve, and it's inhumane to keep alive someone with such a poor quality of life." The resident also argues that a Do Not Attempt Resuscitation (DNAR) order should be written on the basis of futility because CPR is so unlikely to succeed.

THE LIKELIHOOD OF SUCCESS IS VERY SMALL

Some physicians contend that an intervention should be considered futile if the likelihood of success in a given situation is extremely small—for example, no success in the last 100 attempts or less than a 1% chance of success (7). However, there are problems in setting a quantitative, probabilistic concept of futility. Why set the threshold at 1%? Some patients or families might

Futile Intervention

consider a likelihood of success is low. Interventions as futile as agreement could be a range of cases is clear.

NO WORTHWHILE

Futility can be defined as proper goal of medical intervention inappropriate to patient unit (ICU) alive (1).

THE PATIENT'S

In some situations patient's quality of life for patients in a period with other people. The patient has no likelihood.

However, individual physicians. Some people Case 9.4. Indeed, some not regain consciousness than attempt to define.

PROSPECTIVE B

An intervention might the effort and resources unilaterally at the be that such intervention.

PRACTICAL PRO

Several problems on interventions.

JUDGMENTS OF

Physicians often er One study analyzed probabilistic definition of survival after CPR to CPR was 10% or greater believed the probability of life. In the same competent patients though such discussion competent patient found that physicians living (13,14).

consider a likelihood of success of 1% worth pursuing in some circumstances. On the other hand, some physicians might desire to make unilateral decisions to forego interventions whose likelihood of success is 2% or even 5%. Indeed, studies show that physicians commonly describe interventions as futile when the likelihood of success is far greater than 1% (8,9). Hence, even if agreement could be forged on a quantitative threshold for futility, in practice a much broader range of cases is characterized as futile.

NO WORTHWHILE GOALS OF CARE CAN BE ACHIEVED

Futility can be defined only in terms of the goals of care (10). Some ethicists contend that the proper goal of medicine is not simply to correct physiological derangements. For these writers it is inappropriate to prolong life if the patient will not regain consciousness or leave the intensive care unit (ICU) alive (1,7).

THE PATIENT'S QUALITY OF LIFE IS UNACCEPTABLE

In some situations physicians might declare an intervention futile because they believe that the patient's quality of life is unacceptable. For example, some ethicists consider interventions futile for patients in a persistent vegetative state (PVS), who will never regain consciousness or interact with other people (1). They argue that sustaining biological life is not an appropriate goal when the patient has no likelihood of regaining consciousness.

However, individual patients or the public might view the goals of care differently than physicians. Some people regard life as precious even if the patient will not leave the ICU alive, as in Case 9.4. Indeed, some states have public policies that favor prolonging life in patients who will not regain consciousness (11). At a minimum, physicians need to discuss goals with patients rather than attempt to define them unilaterally.

PROSPECTIVE BENEFIT IS NOT WORTH THE RESOURCES REQUIRED

An intervention might be termed futile because the expected outcomes are not considered worth the effort and resources required. However, society as a whole, not an individual physician acting unilaterally at the bedside, needs to decide the allocation of resources (*see* Chapter 30). Asserting that such interventions are futile closes off this difficult but essential debate (12).

PRACTICAL PROBLEMS WITH THE CONCEPT OF FUTILITY

Several problems occur in practice when physicians make unilateral decisions to withhold "futile" interventions.

JUDGMENTS OF FUTILITY ARE OFTEN MISTAKEN OR PROBLEMATIC

Physicians often err when they claim that an intervention has a very low probability of success. One study analyzed cases in which residents had written DNAR orders on the basis of a probabilistic definition of futility (9). In 32% of such cases residents estimated the probability of survival after CPR to be 5% or higher. In 20% of cases the estimated probability of survival after CPR was 10% or greater. Thus, the term "futility" was applied inappropriately when physicians believed the probability of success was much greater than the 1% threshold for futility proposed in the literature. Problems also occur when determinations of futility are based on quality of life. In the same study residents determined that CPR would be futile in this sense for 40 competent patients. Physicians discussed quality of life with only 65% of these patients, even though such discussions were feasible (9). It is ethically problematic for physicians to judge a competent patient's quality of life without talking to the patient directly. Many studies have found that physicians underestimate the extent to which patients believe their lives are worth living (13,14).

UNILATERAL DECISIONS BY PHYSICIANS POLARIZE DISAGREEMENTS

Attempts by physicians to resolve disputes by claiming the power to act unilaterally are likely to antagonize patients and surrogates. Furthermore, declaring one intervention futile might not settle other important issues in a case. For instance, CPR might be futile in a strict sense in a patient with multisystem failure in the ICU. However, a unilateral decision by physicians to withhold CPR would probably worsen disagreements about mechanical ventilation, vasopressor support, and antibiotics for infection.

PHYSICIANS CONFUSE FUTILITY AND BEST INTERESTS

Physicians commonly confuse futility and best interests as a basis for their decisions (10). Even if an intervention cannot be termed futile in a strict sense, physicians may recommend against it because the burdens outweigh the benefits to the patient. Furthermore, doctors may try to persuade the patient or surrogate that the intervention is not in the patient's best interests. Chapter 4 discusses in detail the concept of best interests.

SAFEGUARDS WHEN INTERVENTIONS ARE CONSIDERED FUTILE

Procedural safeguards are necessary to ensure that physicians' unilateral decisions to withhold "futile" interventions are appropriate (Table 9-2). Open discussions of medical futility help guard against errors and abuses. In the original meaning of "futile," there is no controversy that a leaky bucket will not hold water. Similarly, it should not be difficult for a physician to persuade colleagues, the patient or surrogate, or the public that a particular intervention is futile.

OBTAIN A SECOND OPINION

The physician who is considering a unilateral decision to forego a "futile" treatment should obtain a second opinion from a colleague or from the institutional ethics committee. Such second opinions are important because judgments of futility might be flawed.

DISCUSS THE INTERVENTION WITH THE PATIENT OR SURROGATE

Some physicians believe that they need not discuss futile interventions with the patient or surrogate. For example, in Case 9.3 a vast array of interventions would be futile in a strict sense, such as cancer chemotherapy. It would be pointless to tell patients or surrogates of interventions that are irrelevant to the illness at hand. In some cases, however, physicians might not discuss pertinent interventions because they fear that the patient or surrogate will disagree with their assessment that an intervention is futile. Physicians might use the idea of unilateral decisions about futility to avoid unpleasant discussions (15). However, the best approach to such situations is more discussion, not less.

Generally, discussing "futile" treatments with patients or surrogates is beneficial. It shows respect for patients and surrogates and clarifies their expectations, goals, concerns, and needs.

TABLE 9-2

Safeguards When Physicians Unilaterally Decide That an Intervention Is Futile

-
- Obtain a second opinion.
 - Discuss the intervention with the patient or surrogate.
 - Establish explicit guidelines on futility.
-

ENTS

laterally are likely to
futile might not settle
case in a patient with
ns to withhold CPR
support, and antibi-

decisions (10). Even if
commend against it
may try to persuade
rests. Chapter 4 dis-

FILE

ecisions to withhold
al futility help guard
controversy that a leaky
sion to persuade col-
futile.

atment should obtain
Such second opin-

TE

the patient or surro-
a strict sense, such
of interventions that
not discuss perti-
ee with their assess-
eral decisions about
to such situations is

beneficial. It shows
concerns, and needs.

ention

Chapter 14 gives specific suggestions for such discussions. Moreover, such discussions help safeguard against improper uses of the term futility. Almost all patients or surrogates will eventually agree with physicians' judgments that interventions are futile (16).

ESTABLISH EXPLICIT GUIDELINES ON FUTILITY

Health care organizations should develop written guidelines about futile interventions (15,17). Written institutional guidelines demonstrate that unilateral decisions to forego futile interventions are made on the basis of carefully considered standards, not on *ad hoc* reasoning in particular cases. Several cities have developed policies and procedures for futility for a group of hospitals in a community (17-19). A recent Texas statute enacted many provisions of these policies and established an extrajudicial procedure for determining futility and discussing the matter with the patient or family (20). When physicians believe that an intervention is futile and the patient or family disagrees, the patient or family must be invited to meet with the hospital ethics committee. If the ethics committee agrees that the intervention is futile but the family does not, the hospital must try to work with the family to find another physician or institution willing to provide the intervention. After 10 days, if transfer of the patient cannot be arranged, the physician and hospital may withhold or withdraw the futile intervention. In early experience, the ethics committee agrees with the determination of futility in over 90% of cases, and in 86% of these cases the family accepts this judgment (20).

In conclusion, the concepts of futility and "not medically indicated" are intuitively appealing but need to be used extremely carefully. When futility is strictly defined, physicians may, and indeed should, make unilateral decisions to withhold interventions. However, it is problematic for physicians to use these concepts in looser ways to resolve disagreements with patients or families.

REFERENCES

- Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: its meaning and ethical implications. *Ann Intern Med* 1990;112:949-954.
- Youngner SJ. Who defines futility? *JAMA* 1988;260:2094-2095.
- Lo B. Unanswered questions about DNR orders. *JAMA* 1991;265:1874-1875.
- Truog RD, Brett AS, Frader J. The problem with futility. *N Engl J Med* 1992;326:1560-1564.
- Helft PR, Siegler M, Lantos J. The rise and fall of the futility movement. *N Engl J Med* 2000;343(4):293-296.
- Lantos JD, Singer PA, Walker RM, et al. The illusion of futility in clinical practice. *Am J Med* 1989;87:81-84.
- Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: response to critiques. *Ann Intern Med* 1996;125:669-674.
- Prendergast TJ, Luce JM. Increasing incidence of withholding and withdrawal of life support from the critically ill. *Am Rev Resp Dis Crit Care Med* 1997;155:15-20.
- Curtis JR, Park DR, Krone MR, et al. The use of the medical futility rationale in do not attempt resuscitation orders. *JAMA* 1995;273:124-128.
- Kite S, Wilkinson S. Beyond futility: to what extent is the concept of futility useful in clinical decision-making about CPR? *Lancet Oncol* 2002;3:638-642.
- Cruzan v. Harmon. 760 S.W.2d 408.
- Alpers A, Lo B. Futility: not just a medical issue. *Law Med Health Care* 1992;20:327-329.
- Pearlman RA, Uhlmann RF. Quality of life in chronic diseases: perceptions of elderly patients. *J Gerontol* 1988;43:M25-M30.
- Danis M, Patrick DL, Southerland LI, et al. Patients' and families' preferences for medical intensive care. *JAMA* 1988;260:797-802.
- Council on Ethical and Judicial Affairs AMA. Medical futility in end-of-life care. *JAMA* 1999;281:937-941.
- Smedira NG, Evans BH, Grais LS, et al. Withholding and withdrawing of life support from the critically ill. *N Engl J Med* 1990;322:309-315.
- Halevy A, Brody B. A multi-institutional collaborative policy on medical futility. *JAMA* 1996;276:571-574.
- Bay Area Network of Ethics Committees (BANEC) Nonbeneficial Treatment Working Group. Nonbeneficial or futile medical treatment: conflict resolution guidelines for the San Francisco Bay Area. *West J Med* 1999;170:287-290.
- Murphy DJ, Barbour E. GUIDe (Guidelines for the Use of Intensive Care in Denver): a community effort to define futile and inappropriate care. *New Horizons* 1994;2:326-331.
- Fine RL, Mayo TW. Resolution of futility by due process: early experience with the Texas Advance Directives Act. *Ann Intern Med* 2003;138(9):743-746.

ANNOTATED BIBLIOGRAPHY

1. Kite S, Wilkinson S. Beyond futility: to what extent is the concept of futility useful in clinical decision-making about CPR? *Lancet Oncol* 2002;3:638–642.
Helft PR, Siegler M, Lantos J. The rise and fall of the futility movement. *N Engl J Med* 2000;343:293–296.
Two articles that argue that the concept of futility has limited usefulness in clinical practice.
2. Curtis JR, Park DR, Krone MR, et al. The use of the medical futility rationale in do not attempt resuscitation orders. *JAMA* 1995;273:124–128.
Empirical study documenting problems and mistakes that occur when physicians claim that CPR would be futile.
3. Fine RL, Mayo TW. Resolution of futility by due process: early experience with the Texas Advance Directives Act. *Ann Intern Med* 2003;138:743–746.
Describes a statewide futility policy that refers intractable disagreements over futility to the hospital ethics committee.

Physicians can impair be unable to and cause with no nation, a bina and their cl following should be t

CASE 10.1

Mrs. C, a 74-year-old female, had a history of coronary artery disease and underwent percutaneous transluminal angioplasty.

Mrs. C
clinic. She h
when she is
for her. He
the park.

When as
cussions, the
dure, howe
heart and th
be best for
and stubborn
though she
318 mg per

The team
date, the na
serial subtrac

In this case, the nephew should not be so unreasonable as to angiogram

medical decision-making

100:343:293–296.

not resuscitation orders.

if CPR would be futile.
as Advance Directives

to the hospital ethics

Decision-making Capacity

Physicians must respect the autonomous choices of patients. However, illness or medications can impair the capacity of patients to make decisions about their health care. Such patients might be unable to make any decisions, or they might make decisions that contradict their best interests and cause them serious, even irreparable, harm. Decision-making ability falls along a continuum, with no natural threshold for adequate decision-making capacity, yet for any proposed intervention, a binary decision needs to be made: Either patients have adequate decision-making capacity and their choices should be respected or they do not and their preferences can be set aside (1). The following case illustrates how it might be difficult to decide whether decision-making power should be taken away from a patient.

CASE 10.1 Refusal to explain a decision.

Mrs. C, a 74-year-old widow with mild dementia, is admitted for congestive heart failure and angina pectoris that has progressed despite maximal medical therapy (2). In the past 3 years she has suffered two myocardial infarctions. Her physician recommends coronary angiography and, if possible, angioplasty.

Mrs. C recognizes her primary care physician but seldom knows the date or the name of the clinic. She has forgotten to come to several clinic appointments. Her mental functioning gets worse when she is hospitalized. A nephew, her only relative, pays a woman to shop, cook, and clean house for her. He reports that Mrs. C enjoys watching television, attending the senior center, and sitting in the park.

When asked about her wishes for care, Mrs. C says that she wants to go home. After many discussions, the cardiology team convinces her to have the angiogram. On the morning of the procedure, however, she changes her mind, saying that she doesn't want anyone to put a tube into her heart and that she has been in the hospital long enough. Her nephew believes that angioplasty would be best for her but is reluctant to contradict her wishes because she has always been independent and stubborn. Mrs. C is generally adverse to medical interventions. She refused mammography, even though she has a family history of breast cancer. She also refused treatment for a cholesterol level of 318 mg per dL.

The team asks a psychiatrist to see her. On a mental status examination, she does not know the date, the name of the hospital, or the city. She recalls only one of three objects and cannot perform serial subtraction. She refuses to talk further with the psychiatrist, saying that she is not crazy.

In this case Mrs. C's mental functioning is obviously impaired. Is it so impaired that her nephew should assume the authority to make medical decisions for her? Her refusal did not seem so unreasonable to some physicians and nurses. Furthermore, some nurses asked why her consent to angiography was not questioned, only her refusal.

CLINICAL STANDARDS FOR DECISION-MAKING CAPACITY

A patient's decision-making capacity should be subjected to scrutiny in several situations. As in Case 10.1, the patient might refuse a treatment that the physician strongly recommends or vacillate in making a decision. In other cases patients might have conditions that commonly impair decision-making capacity, such as dementia, schizophrenia, or depression. Although these conditions justify closer scrutiny of the patient's decision-making capacity, they are not tantamount to impaired decision-making capacity. Physicians need to test directly the patient's ability to give informed consent for the proposed intervention (3,6,9). Decision-making capacity requires a cluster of abilities (Table 10-1), as outlined below.

THE PATIENT MAKES AND COMMUNICATES A CHOICE

A patient must appreciate that he or she—and not the physician or family members—has ultimate decision-making power. In addition, the patient must be willing to choose among the alternative courses of care. A patient who vacillates repeatedly between consent and refusal is incapable of making a decision, let alone an informed one. Such profound indecision must be distinguished from changing one's mind as the situation changes, as the patient receives more information or advice, or after the patient deliberates.

The patient must communicate his or her choice. A patient who is unable to speak, for example, because of being on a ventilator, does not necessarily lack decision-making capacity. That patient might be able to communicate through writing messages, using an alphabet board, or blinking or nodding in response to questions.

THE PATIENT UNDERSTANDS INFORMATION THAT IS PERTINENT TO THE DECISION AND APPRECIATES ITS RELEVANCE TO THE SITUATION

A patient needs to understand the medical situation and prognosis, the nature of the proposed intervention, the alternatives, the risks and benefits, and the likely consequences of each alternative. The patient needs this information to make an informed decision. In addition to comprehending this information, the patient needs to appreciate that he or she has the disorder and what the consequences of treatment would be. The patient needs to accept that the information that the physician discussed is relevant to his or her own situation. In Case 10.1 the health care team could not determine whether Mrs. C understood that angioplasty usually relieves chest pain but has certain risks.

DECISIONS ARE CONSISTENT WITH THE PATIENT'S VALUES AND GOALS

Choices should be consistent with the patient's character and core values. If Mrs. C wants to be more active without pain, refusing surgery or angioplasty would be inconsistent with her goals. However, many patients do not have well-articulated values and goals or might have multiple,

TABLE 10-1

Clinical Standards for Decision-making Capacity

The patient makes and communicates a choice.

The patient appreciates the following information:

- the medical situation and prognosis
- the nature of the recommended care
- alternative courses of care
- the risks, benefits, and consequences of each alternative.

Decisions are consistent with the patient's values and goals.

Decisions do not result from delusions.

The patient uses reasoning to make a choice.

conflicting goals. Mrs. C might want to return home but also to be more active and pain-free. A choice might be consistent with some goals but not with others. People do not necessarily have a fixed hierarchy of goals and values. Mrs. C might define her goals or set priorities only by deciding about angiography. Thus, physicians should not regard a patient as lacking decision-making capacity merely because that patient cannot articulate a set of general values or goals.

DECISIONS DO NOT RESULT FROM DELUSIONS OR DISTORTED VIEWS OF REALITY

Some patients have delusions that preclude informed decision-making. For instance, Mary Northern was an elderly woman who refused amputation of her gangrenous legs, denying that gangrene had caused her feet to be "dead, black, shriveled, rotting and stinking (10)." Instead, she believed that they were merely blackened by soot or dust. The court declared her incompetent because she was "incapable of recognizing facts which would be obvious to a person of normal perception (10)." The court said that if she had acknowledged that her legs were gangrenous but refused amputation because she preferred death to the loss of her feet, she would have been considered competent to refuse the surgery.

THE PATIENT USES REASONING TO MAKE A CHOICE

Processing information logically is another element of the capacity to make medical decisions. Patients should compare and weigh the various options for care (11). This requirement does not require the patient to choose what most people consider reasonable in the situation. Unconventional decisions do not necessarily imply lack of decision-making capacity. Expectations for reasoning must take into account that many people do not deliberate but instead rely on emotional or intuitive factors in making important decisions.

ASSESSMENTS OF DECISION-MAKING CAPACITY SHOULD TAKE INTO ACCOUNT THE CLINICAL CONTEXT

Assessments must consider the patient's functional abilities, the demands of the specific clinical situation, and the harm that might result from her choice. Some writers have suggested that a patient who chooses an option that has great risk and little prospect of benefit should meet higher standards for decision-making capacity than a patient who chooses an option that has great prospect of benefit and little risk (6,12,13). The benefits and risks of alternatives should also be taken into account; a patient who chooses an option that has less benefit and greater risk than the alternatives should be held to a stricter standard of decision-making capacity. Also, the nature of the intervention might be important. A patient might be given more leeway to refuse disfiguring surgery, such as amputation, than treatments with less drastic side effects. Such a sliding scale offers more protection to patients when the potential harm resulting from their decisions is greater. According to this view, it seems plausible in Case 10.1 to apply a more rigorous standard of capacity when Mrs. C refuses treatment for symptomatic, life-threatening cardiac disease than when she refuses screening tests or treatment for cardiac risk factors. Although such a sliding scale is intuitively appealing, it might be problematic in practice. People are likely to disagree over what risks are serious and over what standard should be required for a particular decision. A sliding scale might allow physicians to exercise inappropriate control over patients with whom they disagree. To guard against such problems, physicians need to define explicitly the criteria they are using in assessing a patient's decision-making capacity.

ASSESSING THE CAPACITY TO MAKE DECISIONS

Many helpful and practical suggestions for determining decision-making capacity have been offered (9,14). The assessment presupposes that the patient has received adequate information about his or her condition and the interventions. If there is any doubt, the physician needs to repeat the information.

- "Tell m
- "What

- "What
- "I've d
- how we

- "Tell m
- "Help m
- "Tell m

In addition
patient, p
whether d

Clinicians
ical deci
open, inn
and langu

Howev
stands the

(16). For e
angioplast
make an i

In seve
make deci
amputation
he was dis
The proba
that would
able" but n

In anod
program C
that her "b
psychiatric
unable to f
about she i

Psychiatrist
and 144
to respect
risk to eval

Decision Making

and pain-free. A patient necessarily has a right to refuse only by deciding decision-making goals.

FACTS OF REALITY

ance, Mary North-
ying that gangrene
stead, she believed
petent because she
normal perception
enous but refused
e been considered

medical decisions.
quirement does not
nation. Unconven-
pectations for rea-
ly on emotional or

WHO ACCOUNT

ne specific clinical
e suggested that a
hould meet higher
ion that has great
es should also be
eater risk than the
Also, the nature of
refuse disfiguring
ch a sliding scale
ecisions is greater.
standard of capac-
ase than when she
iding scale is intu-
ee over what risks
m. A sliding scale
n they disagree. To
they are using in

capacity have been
quate information
ian needs to repeat

Decision-making Capacity

71

DOES THE PATIENT UNDERSTAND THE DISCLOSED INFORMATION?

Helpful questions include:

- "Tell me what you believe is wrong with your health now."
- "What is angiography likely to do for you?"

DOES THE PATIENT APPRECIATE THE CONSEQUENCES OF HIS OR HER CHOICES?

The physician can ask:

- "What do you believe will happen if you do not have angiography?"
- "I've described the possible benefits and risks of angiography. If these benefits or risks occurred, how would your everyday activities be affected?"

DOES THE PATIENT USE REASONING TO MAKE A CHOICE?

The doctor can make such requests as:

- "Tell me how you reached your decision. . . ."
- "Help me understand how you decided to refuse the angiogram."
- "Tell me what makes angiography seem worse than the alternatives."

In addition, it is helpful to talk to family and friends, nurses, and other physicians caring for the patient, particularly when the physician does not know the patient well. These persons can clarify whether the patient's mental function or choices have changed over time.

THE ROLE OF MENTAL STATUS TESTING

Clinicians often use mental status tests to assess whether a patient has the capacity to make medical decisions. Such tests evaluate orientation of the subject to person, place, and time, attention span, immediate recall, short-term and long-term memory, ability to perform simple calculations, and language skills (15).

However, mental status tests are less useful than directly assessing whether the patient understands the nature of the intervention, the risks and benefits, the alternatives, and the consequences (16). For example, Mrs. C scored poorly on standard mental status tests, but if she appreciates that angioplasty would probably improve her chest pain and shortness of breath, she has the capacity to make an informed refusal.

In several court rulings patients with abnormal mental status tests were found competent to make decisions about health care. For example, a 72-year-old man who withdrew his consent for amputation of his gangrenous legs was found competent even though one psychiatrist found that he was disoriented to the place and to the people around him and had visual hallucinations (17). The probate judge found that "his conversation did wander occasionally but to no greater extent than would be expected of a 72-year-old man in his circumstances." The patient hoped "for a miracle" but realized that "there is no great likelihood of its occurrence."

In another case a 77-year-old woman was found competent to refuse amputation of her leg for gangrene (18). Testimony indicated that she was "lucid on some matters and confused on others," that her "train of thought sometimes wanders," and that "her conception of time is distorted." One psychiatrist claimed that her refusal to discuss the amputation with him indicated that "she was unable to face up to the problem." The court found that she understood that in "rejecting the amputation she is, in effect, choosing death over life."

CONSULTATION BY PSYCHIATRISTS

Psychiatrists might be helpful in evaluating patients whose decision-making capacity is questionable (4,14,19). Psychiatrists are skilled at interviewing patients with mental impairment. Compared to nonspecialists, they might be more successful at engaging the patient in discussions and better able to evaluate the patient's understanding of the proposed intervention. In addition, psychiatrists

specialize in diagnosing and treating mental illnesses that might impair a patient's decision-making capacity. Psychiatrists are also skilled at identifying and resolving interpersonal and intrapsychic conflicts that impair decision making (19).

Attending physicians can readily acquire the skills to assess patients' decision-making capacity, and routine psychiatric consultation is not necessary (20). Ultimately, attending physicians are responsible for judging whether the patient lacks decision-making capacity.

ENHANCING THE CAPACITY OF PATIENTS TO MAKE DECISIONS

Impairments in decision-making capacity might be reversible if underlying medical or psychiatric conditions are treated. In addition, physicians can enhance patient understanding of pertinent information by presenting information in simple language, in small chunks, slowly and repeatedly over time. Diagrams and videotapes might improve comprehension. Furthermore, the presence of family members or friends can help reduce anxiety, correct misunderstandings, and focus on the salient issues.

ENGAGING THE PATIENT IN DISCUSSIONS

Patients like Mrs. C might refuse to answer questions or explain their decisions. They need to understand that lack of cooperation might lead to a determination of impaired decision-making capacity and loss of the power to make health care decisions. However, repeated attempts to assess decision-making capacity or to persuade them might be counterproductive. Patients might be angry at losing control or resent being badgered. In turn, health care workers might feel frustrated.

DECISION-MAKING CAPACITY IN SPECIFIC CLINICAL SITUATIONS

MENTAL ILLNESS AND DECISION-MAKING CAPACITY

Many patients with mental illness are competent to make decisions about their medical care. However, lack of decision-making capacity is more common in certain psychiatric conditions. Patients with schizophrenia or depression commonly fail to appreciate the relevance of information to their situation. According to one study, among inpatients with schizophrenia, 35% did not acknowledge their symptoms and diagnosis (21). Furthermore, 13% to 14% of patients with schizophrenia or major depression denied the potential benefit of treatment.

Psychiatric illness might also impair decision-making capacity more subtly (22). Patients who are depressed might overemphasize the risks of treatment, underestimate the benefits, believe that treatment is less likely to be successful for them than for others, or feel unworthy of the intervention.

Psychiatric patients might be so gravely disabled or unable to care for themselves that they might be involuntarily committed (*see* Chapter 40). However, involuntary commitment does not empower physicians to give whatever medical treatment they consider advisable. If such a patient refuses treatment for medical problems, an appropriate surrogate or a separate court order is needed to authorize treatment.

UNCONVENTIONAL DECISIONS BASED ON RELIGIOUS BELIEFS

Patients might refuse effective medical treatments because of religious beliefs. Religious beliefs are matters of faith; empirical evidence and reasoning are not pertinent. In the United States freedom of religion is deeply respected. Furthermore, it is troubling for physicians to label some religious beliefs as acceptable and others as not. Thus, refusals of treatment by competent adults on religious grounds are accepted. (Parental refusals of effective treatment for children may be overridden, as is discussed in Chapter 37.) Religious beliefs need not be articulated as formal or orthodox doctrines. As one court ruling declared, beliefs that others consider "unwise, foolish, or ridiculous" do not render a person incompetent (23). Indeed, informed consent would be meaningless if such individualistic refusals were not respected, even though they conflicted with medical or popular wisdom.

The physician's inquiry generally is limited to whether the religious beliefs are sincere in the sense that they antedate the illness and are consistent with prior actions (24) and whether other

patient's decision-making
social and intrapsychic

decision-making capacity,
including physicians are

medical or psychiatric
of pertinent informa-
repeatedly over time.
presence of family mem-
the salient issues.

sions. They need to
and decision-making
and attempts to assess
Patients might be
might feel frustrated.

INS

medical care. How-
conditions. Patients
information to their
did not acknowledge
the schizophrenia or

(22). Patients who
benefits, believe that
of the intervention.
themselves that they
commitment does not
be. If such a patient
rate court order is

i. Religious beliefs
the United States
ians to label some
of competent adults
or children may be
related as formal or
"unwise, foolish,
consent would be
ey conflicted with

are sincere in the
and whether other

aspects of decision-making are problematic. Some patients have religious delusions or hallucinations. For example, a patient might believe that he is Christ, that the devil has caused his colon cancer, or that he should refuse surgery because it is God's will that he suffer. Because of his delusions, he is not capable of making informed decisions. It does not matter that his delusions are based on religious ideas.

EMERGENCIES

A patient with questionable decision-making capacity might present with an emergency condition that requires immediate treatment. Rather than evaluating the patient's decision-making capacity, physicians should provide emergency care unless it is known that the patient or surrogate would refuse such care. This approach is justified by implied consent to emergency care (see Chapter 3).

CARING FOR PATIENTS WHO LACK DECISION-MAKING CAPACITY

After physicians determine that a patient lacks decision-making capacity, advance directives or surrogate decision-making should guide further care (see Chapters 12 and 13).

Even if a patient lacks the capacity to make decisions, his or her stated preferences should be given substantial consideration. For instance, mentally incapacitated patients might balk at phlebotomy or x-rays, sometimes screaming their refusal. Even if the courts declared such a patient incompetent, it would be morally and emotionally repugnant to impose interventions on an unwilling patient. Health care workers might consider it inhumane to force a patient to undergo a highly invasive intervention when he or she cannot understand its purpose and benefits. Furthermore, future cooperation might be undermined. It is preferable if the patient assents to interventions decided on by a surrogate or court, even if that patient cannot give informed consent. Persuasion, cajoling, and asking family members and friends to talk to the patient are acceptable ways to try to gain the patient's cooperation. Often, a patient will agree to treatment after caregivers have listened to his or her objections, modified the treatment plans, or changed the hospital routine.

In summary, physicians commonly decide that patients lack the capacity to make informed decisions about their care without resorting to the courts. Physicians need to understand the clinical standards for decision-making capacity and be able to apply these standards in specific cases. Good communication skills are crucial for assessing decision-making capacity.

REFERENCES

1. Brock DW. *Life and Death*. New York: Cambridge University Press, 1993.
2. Lo B. Assessing decision-making capacity. *Law Med Health Care* 1990;18:193-201.
3. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Making Health Care Decisions*. Washington, DC: U.S. Government Printing Office, 1982.
4. Appelbaum PS, Lidz CW, Meisel A. *Informed consent: legal theory and clinical practice*. New York: Oxford University Press, 1987:266.
5. Meisel A. *The right to die*. New York: John Wiley & Sons, 1989.
6. Buchanan AE, Brock DW. *Deciding for others*. Cambridge: Cambridge University Press, 1989.
7. Beauchamp TL, Childress JF. *Principles of biomedical ethics*, 4th ed. New York: Oxford University Press, 1994.
8. Meisel A. *The right to die*, 2nd ed. New York: John Wiley & Sons, 1995.
9. Grisso T, Appelbaum P. *Assessing competence to consent to treatment: a guide for physicians and other health professionals*. New York: Oxford University Press, 1998.
10. State Dep't of Human Resources v. Northern. 563 S.W.2d 197 (Tenn. Ct. App. 1978).
11. Grisso T, Appelbaum P. *Assessing competence to consent to treatment: a guide for physicians and other health professionals*. New York: Oxford University Press, 1998:52-58.
12. Grisso T, Appelbaum P. *Assessing competence to consent to treatment: a guide for physicians and other health professionals*. New York: Oxford University Press, 1998:22-26.
13. Drane JF. Competency to give an informed consent. *JAMA* 1984;252:925-927.
14. Applebaum PS, Grisso T. Assessing patients' capacities to consent to treatment. *N Engl J Med* 1988;319:1635-1638.
15. Kane RL, Ouslander JG, Abrass IB. *Essentials of clinical geriatrics*, 2nd ed. New York: McGraw-Hill, 1989.
16. Grisso T, Appelbaum P. *Assessing competence to consent to treatment: a guide for physicians and other health professionals*. New York: Oxford University Press, 1998:90-91.
17. In re Quackenbush. 156 N.J. Super. 282, 383 A.2d 785 (1978).

18. Lane v. Candura. 6 Mass. App. 377, 376 N.E.2d 1232 (1978).
19. Perl M, Shelp EE. Psychiatric consultation masking moral dilemmas in medicine. *N Engl J Med* 1982;307:618-621.
20. Grisso T, Appelbaum P. *Assessing competence to consent to treatment: a guide for physicians and other health professionals*. New York: Oxford University Press, 1998:77-80.
21. Appelbaum PS, Grisso T. The MacArthur Treatment Competence Study, I: mental illness and competence to consent to treatment. *Law Hum Behav* 1995;19:105-126.
22. Bursztajn HJ, Gutheil TG, Brodsky A. *Affective disorders, competence, and decision making*. In Gutheil TG, Bursztajn HJ, Brodsky A, Alexander V, eds. *Decision making in psychiatry and the law*. Baltimore: Williams & Wilkins, 1991:153-170.
23. In re Brooks. 32 Ill.2d 361, 205 N.E.2d 435 (1965).
24. Grisso T, Appelbaum P. *Assessing competence to consent to treatment: a guide for physicians and other health professionals*. New York: Oxford University Press, 1998:47-48.

ANNOTATED BIBLIOGRAPHY

1. Grisso T, Appelbaum P. *Assessing competence to consent to treatment: a guide for physicians and other health professionals*. New York: Oxford University Press, 1998.
Lucid, practical, and comprehensive discussion of how to assess decision-making capacity.
2. Buchanan AE, Brock DW. *Deciding for others*. Cambridge: Cambridge University Press, 1989.
Comprehensive discussion of different definitions and standards for decision-making capacity.

Competence
In some cases
Although con-
stant for phys-
icians informed,
the problems
patient refuse

REASONS

RESPECT FOR

Honoring refu-
sals individuality.
their care (1-4
statement is fu-
then logically
the Constitution
of case law say

IMPOSING A

As a practical
means patient.
survive and in
of treatment to

SCOPE OF R

Competent pati-
with few case
decision, reason-
ing to refuse
are not required

Refusal of Treatment by Competent, Informed Patients

Competent and informed patients may refuse interventions that their physicians recommend. In some cases physicians may hesitate to accept refusals that jeopardize the patient's life or health. Although concern for a patient's well-being is commendable, as discussed in Chapter 4, it is important for physicians to understand the strong ethical and legal reasons for respecting refusals made by informed, competent patients. This chapter discusses the reasons for respecting such refusals, the problems that result from refusals of transfusions by Jehovah's Witnesses, and restrictions on patient refusal.

REASONS FOR RESPECTING PATIENT REFUSALS

RESPECT FOR PATIENT AUTONOMY

Honoring refusal of treatment by competent, informed patients respects their self-determination and individuality. Ethically, physicians should respect the autonomy of persons to make decisions about their care (1–4). Patients should be free of unwanted medical interventions. The option of declining treatment is fundamental to the concept of informed consent. If patients must consent to treatment, then logically they have the right to decline treatment. The U.S. Supreme Court has suggested that the Constitution protects a competent patient's refusal of life-sustaining treatment (5). A large body of case law supports the right of competent, informed patients to refuse treatment (6).

IMPOSING MEDICAL INTERVENTIONS WOULD BE UNACCEPTABLE

On a practical level it is difficult to imagine imposing unwanted medical interventions on a competent patient. Sedating or restraining patients to impose treatment over their objections seems intrusive and inhumane. Most people would find such means repugnant, even if the original refusal of treatment was unwise.

SCOPE OF REFUSAL

Competent patients are permitted to refuse virtually any treatments, even highly beneficial ones with few side effects. The range of interventions includes surgery, mechanical ventilation, renal dialysis, antibiotics, cardiopulmonary resuscitation, and tube feedings (6). Competent patients have a right to refuse treatment even if such refusal might shorten their lives or lead to their deaths. They are not required to have a terminal illness as a condition for refusing treatment.

Competent patients may refuse treatment even if their family, friends, or physicians disagree with them. As one court ruling declared, even decisions that are "unwise, foolish, or ridiculous (7)" might need to be respected. Indeed, informed consent would be meaningless unless patients could refuse interventions for highly personal reasons or make decisions that conflict with medical or popular wisdom.

JEHOVAH'S WITNESS CASES

Jehovah's Witnesses do not accept blood transfusions, basing their refusal on an interpretation of the Bible (8). They believe that although a blood transfusion might save their corporeal life, it will deprive them of everlasting salvation. Their refusals are clearly articulated, are usually steadfast over time, and are supported by their family and friends. Refusals of blood transfusions by Jehovah's Witnesses might be distressing to physicians because, from a purely clinical perspective, the benefits of transfusion are great and the risks trivial. Many patients are young, previously healthy, and can be restored to perfect health.

REACTIONS OF HEALTH CARE PROVIDERS

Jehovah's Witnesses generally consent to other interventions, such as surgery, if transfusions are not used. Physicians might feel that Jehovah's Witnesses, by refusing transfusions but agreeing to other care, unnecessarily compromise medical outcomes, make their job more difficult, and require them to provide substandard care. Physicians might believe that they are being asked to accomplish the goal of saving the patient's life without using the best available means. Some surgeons complain that operating on a Jehovah's Witness without transfusions is like having to operate with one hand tied behind their back. They have less margin for error or complications. On a psychological level, some physicians resent the loss of control over the patient's care. Some health care workers might also blame the patient for making their jobs more complicated. Many surgeons and anesthesiologists prefer not to treat Jehovah's Witnesses. Often, however, transferring such patients to another institution or physician is impractical.

Frustrated health care workers might develop imaginative plans for administering blood to Jehovah's Witnesses. Some physicians suggest waiting until such patients are unconscious and then asking if they object to a transfusion. Because patients are then no longer able to refuse, these physicians would administer blood. Other physicians advocate simply giving transfusions after patients are under anesthesia and not telling them about it. Both such actions, however, are unacceptable because they are deceptive and undermine trust in physicians.

Health care workers need to appreciate that without transfusions medical outcomes for Jehovah's Witness are often quite good, even though care is more difficult. For example, operative mortality for open heart surgery on Jehovah's Witnesses has been reported as acceptably low, using intraoperative cell salvage and other blood conservation techniques (9).

LEGAL ISSUES

The courts have consistently upheld refusals of blood transfusions by competent adult Jehovah's Witnesses (10-13). Recent controversies have involved incompetent Jehovah's Witnesses. Some physicians object that wallet cards signed by Jehovah's Witnesses are not sufficient evidence that the patient made an informed decision (14).

PRACTICAL SUGGESTIONS

Physicians caring for Jehovah's Witnesses can take several steps to ensure that the patient's refusal of transfusions is informed and steadfast. First, the physician should ask the adult patient about transfusions when no family members, friends, or religious advisors are present. This lessens the chance that the patient feels coerced into refusing. When alone, some Jehovah's Witnesses will agree to transfusions. Second, the physician should ask patients whether they would accept transfusions if they are ordered by a court. Some Jehovah's Witnesses will accept a transfusion as long as they do not personally consent to it. Under these circumstances many judges are willing to order

physicians disagree
or ridiculous (7)"
less patients could
it with medical or

n interpretation of
temporal life, it will
usually steadfast
transfusions by Jeho-
ah's perspective, the
previously healthy,

transfusions are not
it agreeing to other
t, and require them
to accomplish the
surgeons complain
rate with one hand
psychological level,
are workers might
and anesthesiolo-
patients to another

ring blood to Jeho-
ah's and then ask-
e to refuse, these
transfusions after
however, are unac-

outcomes for Jeho-
ah's. operative mor-
tality is low, using

an adult Jehovah's
Witnesses. Some
recent evidence that

the patient's refusal
an adult patient about
it. This lessens the
Jehovah's Witnesses will
could accept trans-
fusion as long
are willing to order

that transfusions be given. Third, some Jehovah's Witnesses will refuse all blood products but others will accept various blood components. Most will accept erythropoietin and fluorinated blood substitutes. Fourth, physicians should ask whether the patient has any other concerns about receiving blood, such as a risk of human immunodeficiency virus (HIV) infection or hepatitis. If the underlying reason for refusal is really a fear of infection, this concern should be addressed directly.

Having ensured that the refusal is steadfast and informed, health care workers should respect the patient's decision. From the point of view of a Jehovah's Witness, the decision to refuse transfusions is simple. They would be pleased to survive the hospitalization, but as one patient put it, "What good is a few years of life compared to everlasting damnation (15)?" Even if health care workers do not agree with this belief, they need to respect it. Continuing to try to convince a Jehovah's Witness shows disrespect. Furthermore, using deception to administer blood cannot be condoned.

When an adult Jehovah's Witness who requires a transfusion lacks decision-making capacity, the situation is more complicated. Advance directives that reflect informed decisions should be respected, as Chapter 12 discusses. Many Jehovah's Witnesses have completed wallet-sized "blood cards" declaring they would refuse transfusions. The ethical validity of these cards has been questioned because completion of the cards might have been coerced by peer pressure and because the patient might not have been informed about the risks and benefits of transfusions (14).

Physicians should respond differently if the patient is a minor and the parents are refusing a medically indicated transfusion (*see* Chapter 37). In this situation physicians should ask a court to approve the transfusion. As one court declared, parents are "not free to make martyrs of their children (16)."

RESTRICTIONS ON REFUSAL

The right of competent, informed patients to refuse medical treatment may be limited in certain situations.

COMMUNICABLE DISEASES

In certain circumstances competent patients may be required to undergo treatment against their wishes in order to prevent harm to third parties. The clearest examples are infectious diseases that can be transmitted by casual contact, such as tuberculosis (17,18). To reduce the risk of transmitting a serious disease to other persons, infected individuals may be required to be treated or else be quarantined until they no longer pose a risk to others.

COMPELLED TREATMENT OF PREGNANT WOMEN

In several cases the courts have ordered pregnant women to undergo cesarean sections or blood transfusions over their objections, allegedly to protect the health of the fetus. These rulings, however, have been sharply criticized for violating the woman's bodily integrity and right of self-determination. Recent court rulings have rejected interventions against the wishes of the pregnant woman (19-21).

Trying to prevent harm to the fetus that will be carried to term is praiseworthy (*see* Chapter 39). However, in most situations in pregnancy compelled treatment is not feasible. In diabetes or drug addiction, interventions must be continued over an extended period, the cooperation of the pregnant woman is needed, and the infringement of her autonomy caused by ongoing forced treatment is substantial.

TREATING COMPETENT PATIENTS FOR THEIR OWN BENEFIT

Providing interventions over the objections of a competent patient in order to prevent harm to third parties needs to be clearly distinguished from providing treatment in order to prevent harm to the patient. The physician's duty to prevent harm to competent patients is considered weaker than the duty to prevent harm to unsuspecting third parties. Physicians should try to persuade patients and to negotiate a mutually acceptable plan of care (*see* Chapter 4). They may not, however, override the informed decisions of a competent patient because they believe it would be better for that patient.

In some situations physicians might be tempted to administer treatment to prevent serious harm to patients. Jonsen et al. discuss the perplexing case of a young man with bacterial meningitis who refused antibiotics (22). The patient shows no indication of impaired decision-making capacity other than his "enigmatic refusal" of treatment. As they present the case, there is no time for prolonged discussion. Rather than allow the patient to die from such a readily treatable infection, these authors advocate administering antibiotics because they believe that "something essential is missing in the case." Indeed, the authors later disclose that earlier the patient's cousin had died from an anaphylactic reaction to penicillin and that this incident had led to his refusal.

This is admittedly a difficult case, and difficult cases often lead to bad generalizations. Although it is troubling to allow a patient to die from an easily treatable infection, it is also troubling to override the refusal of a patient when the only evidence of impaired decision-making capacity is the patient's refusal of treatment. Without hindsight, it is problematic to establish a rule that such patients can be considered to have impaired decision-making capacity. Any such rule would give physicians virtually unlimited power to override patients who cannot provide satisfactory reasons for refusing treatment.

In summary, there are cogent ethical and legal reasons to accept refusals of treatment by competent and informed patients. Subsequent chapters discuss how physicians can try to persuade patients to accept beneficial interventions while respecting their right to refuse.

REFERENCES

1. Lo B, Jonsen AR. Clinical decisions to limit treatment. *Ann Intern Med* 1980;93:764-768.
2. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Making health care decisions*. Washington: U.S. Government Printing Office, 1982.
3. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to forego life-sustaining treatment*. Washington: U.S. Government Printing Office, 1983.
4. American College of Physicians. American College of Physicians Ethics Manual. *Ann Intern Med* 1998;128:576-594.
5. Lo B, Steinbrook R. Beyond the Cruzan case: the U.S. Supreme Court and medical practice. *Ann Intern Med* 1991;114:895-901.
6. Meisel A. *The right to die*, 2nd ed. New York: John Wiley and Sons, 1995.
7. *In re Brooks*. 32 Ill.2d 361, 205 N.E.2d 435 (1965).
8. Sheldon M. Ethical issues in the forced transfusion of Jehovah's Witness children [see comments]. *J Emerg Med* 1996;14:251-257.
9. Rosengart TK, Helm RE, DeBois WJ, et al. Open heart operations without transfusion using a multimodality blood conservation strategy in 50 Jehovah's Witness patients: implications for a "bloodless" surgical technique. *J Am Coll Surg* 1997;184:618-629.
10. Furrow BR, Johnson SH, Jost TS, et al. *Health law: cases, materials and problems*. St. Paul: West Publishing Co, 1991.
11. Meisel A. *The right to die*, 2nd ed. New York: John Wiley and Sons, 1995:538-542.
12. *Fosmire v. Nicoleau*, 552 N.E.2d 77 (N.Y. 1990).
13. *Norwood Hosp. v. Munoz*, 564 N.E.2d 1017 (Mass. 1991).
14. Migden DR, Braen GR. The Jehovah's Witness blood refusal card: ethical and medicolegal considerations for emergency physicians. *Acad Emerg Med* 1998;5:815-824.
15. *In re Osborne*, 294 A. 2d 372 (D.C. 1972).
16. *Prince v. Massachusetts*, 321 U.S. 158 (1944).
17. Oscherwitz T, Tulskey JP, Roger S, et al. Detention of persistently nonadherent patients with tuberculosis. *JAMA* 1997;278:843-846.
18. Gasner MR, Maw KL, Feldman GE, et al. The use of legal action in New York City to ensure treatment of tuberculosis. *N Engl J Med* 1999;340:359-366.
19. Curran W. Court-ordered cesarean sections receive judicial defeat. *N Engl J Med* 1990;323:489-492.
20. Levy JK. Jehovah's Witnesses, pregnancy, and blood transfusions: a paradigm for the autonomy of all pregnant women. *J Law Med Ethics* 1999;27:171-189.
21. Goldblatt AD. Commentary: no more jurisdiction over Jehovah. *J Law Med Ethics* 1999;27:190-193.
22. Jonsen A, Siegler M, Winslade W. *Clinical Ethics*, 3rd ed. New York: Macmillan Publishing Company Inc, 1991:61-63.

ANNOTATED BIBLIOGRAPHY

1. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to forego life-sustaining treatment*. Washington: US Government Printing Office, 1983.
Lucid and thoughtful exposition of refusal of treatment by patients.
2. Meisel A. *The right to die*, 2nd ed. New York: John Wiley and Sons, 1995.
Comprehensive legal treatise that describes court rulings permitting competent patients to refuse treatment.

Standards for Decisions When Patients Lack Decision-making Capacity

When patients lack decision-making capacity, physicians must address two questions:

- What standards should be used when patients cannot give informed consent or refusal?
- Who should act as surrogate for such patients?

This chapter addresses the first question, discussing advance directives, substituted judgments, and the patient's best interests. These should be viewed as a hierarchy: decisions based on advance directives generally should take priority over those grounded in substituted judgments, which in turn should supersede decisions based on best interests (Table 12-1). Chapter 13 addresses the second question.

ADVANCE DIRECTIVES

Many patients fear that they will lose control over care if their decision-making capacity is impaired. Advance directives are statements by competent patients that indicate *who* should act as surrogate or *what* interventions they would accept or refuse in case they should lose decision-making capacity. Although patients are still competent, they give informed consent or refusal. Advance directives respect patients by allowing their preferences and values to guide care even when they can no longer make informed decisions. In addition, advance directives allow patients to relieve stress on family members who must make decisions for them (1).

Advance directives are most useful when they identify whom the patient trusts to make decisions if he or she loses decision-making capacity. Many patients also want to provide substantive directives about what interventions they would want or not want. In most cases, however, the proxy will need to interpret the patient's previous statements rather than simply implement them. Thus, the patient needs to trust the proxy's judgment and discretion. The following case illustrates the usefulness and limitations of advance directives.

CASE 12.1 Oral advance directives.

Mrs. A, a 76-year-old widow with Alzheimer disease, lives in a nursing home. She often does not recognize relatives and friends or respond when asked questions. She requires assistance with dressing, bathing, and eating. When still lucid, she told her children and her friends many times that she wanted "no heroics" if she became senile. After visiting a neighbor who was in intensive care, unconscious after a severe stroke, she told her son, "That is not living. I don't want to die plugged into a machine, unable to recognize my family and having to depend on others to take care of me. If I'm like that, just let me die in peace."

TABLE 12-1

Standards for Making Decisions When Patients Lack Decision-making Capacity

Advance directives.
Oral statements to family members or friends
Oral statements to physicians
Written documents
Substituted judgments.
Best interests of the patient.

Mrs. A develops pneumonia and sepsis. Her son and daughter remind the physician of these conversations and ask him not to administer antibiotics for the infection or transfer her to an acute care hospital. However, her brother strongly believes that life-sustaining treatment should be provided regardless of her previous statements or expected quality of life. He asserts, "Life is sacred; you can't just let her die." The brother adds, "She's a totally different person. She was so afraid of being senile. But look at her now. She's not suffering. Even though she usually doesn't recognize us, she smiles when I hold her hand or when I play music on the radio."

TYPES OF ADVANCE DIRECTIVES

Oral Statements to Family Members or Friends

Conversations with relatives or friends about what interventions they would want or not want in future situations are the most common advance directives (2,3). Such discussions are frequently used in everyday clinical practice to guide decisions for patients who have lost decision-making capacity.

Limitations of oral directives. People might comment about the care of other people without intending to direct their own future care. They might also state preferences without thinking deeply about them. In addition, observers might not accurately recall a patient's statements or might disagree over what the patient said.

Legal status of oral directives. Although oral directives are commonly used in decisions to provide or forego an intervention, a few states severely restrict their use (4). Courts have ruled that advance directives must be "clear and convincing," which requires stronger evidence than a "preponderance of the evidence" but less evidence than "beyond a reasonable doubt." Applying this standard strictly, several states have rejected typical oral advance directives unless they mention the specific intervention and clinical situation at hand—for example, a feeding tube in severe dementia (5). Although most court rulings have concerned cases of severe cognitive impairment, New York requires such clear and convincing evidence even for patients with incurable cancer. Courts in other states, however, have accepted oral statements similar to those by Mrs. A in Case 12.1 as clear and convincing (5).

Evaluating the trustworthiness of oral directives. Certain characteristics make oral advance directives more trustworthy guides to whether the patient wanted an intervention.

- The patient's preferences are *informed*. Patients who have experienced serious illness or who have had relatives or friends with serious illness are more likely to be informed.
- The directive indicates what *specific treatments* the patient would want or not want in *various clinical situations* rather than simply expressing general preference or values.
- The directive is *repeated* over time, in different situations, to various individuals. Such consistency makes it more likely that the choices are carefully considered and based on deeply held values.

Standards for

Oral Statements

discussions with oral statements from physicians discussed with

Written Documents

All states have (4,7,8). Patients are needed to or who follow written and liability and powers and patient. The courts of oral statements. state the consequences about 25% of patients

living with treatment if they (PVS). Various states living with only intervention phase includes artificial nutrition and hydration

Health care medical decision making a durable continue to make decision-making of her children. Certain people are the surrogate make unless they are the patient is inconsistent with evidence of the state requirements sustaining treatment advance directives

LIMITATIONS**Advance Directives**

Even after discussion cannot talk and are always coma resuscitation (Chest compressions restarting the heart) moves about treatment

Patients also colon cancer, with 39% believed that

physician of these con-
 sider her to an acute care
 it should be provided
 life is sacred; you can't
 afraid of being senile.
 ize us, she smiles when

I want or not want in
 decisions are frequently
 lost decision-making

other people without
 without thinking deeply
 statements or might

used in decisions to
 4). Courts have ruled
 onger evidence than a
 doubt." Applying this
 unless they mention the
 life in severe dementia
 impairment, New York
 cancer. Courts in other
 Case 12.1 as clear and

ics make oral advance
 ion.

erious illness or who
 rmed.

or not want in various
 es.

ividuals. Such consis-
 based on deeply held

Oral Statements to Physicians

Discussions with physicians are more common than written advance directives (2–4,6). Unlike some oral statements to relatives or friends, directives to physicians are not casual comments. Moreover, physicians can check whether directives are informed. For instance, a physician could have discussed with Mrs. A how most patients with moderate dementia appear to enjoy many activities.

Written Documents

All states have enacted laws authorizing living wills or the appointment of health care proxies (4,7,8). Patients complete a formal legal document that must be witnessed or notarized. A lawyer is not needed to complete these documents. Many states honor forms from other states. Caregivers who follow written directives that meet state requirements are given immunity from civil and criminal liability and professional disciplinary actions. Because statutes vary from state to state, caregivers and patients need to be familiar with their state's laws.

The courts consider written advance directives more reliable evidence of patient choices than oral statements. Courts presume that patients are more likely to think about the issues and to appreciate the consequences of their actions if they complete a formal legal document. However, only about 25% of patients have given written advance directives (9–13).

Living wills. In living wills, patients direct their physicians to withhold or withdraw life-sustaining treatment if they develop a terminal condition or, in some states, enter a persistent vegetative state (PVS). Various states define "terminal condition" differently, usually only in general terms. In most states living wills would not cover conditions such as Alzheimer disease. Patients typically may refuse only interventions that "merely prolong the process of dying." People may disagree on whether this phrase includes antibiotics for pneumonia in Case 12.1. Some states do not allow patients to decline artificial nutrition and hydration through living wills. Because of these limitations, living wills are less flexible and comprehensive than the health care proxy (14–16).

Health care proxy. Competent patients might appoint a health care proxy or agent to make medical decisions if they were to lose decision-making capacity. In some states this process is called *executing* a durable power of attorney for health care. As long as patients remain competent, they continue to make their own health care decisions. This proxy, typically a relative or close friend, has decision-making priority over other potential surrogates. In Case 12.1, if Mrs. A had appointed one of her children as health care proxy, her brother would have no authority to make health decisions. Certain people might not serve as surrogates because of potential conflicts of interest. In California the surrogate may not be the treating physician or employees of the treating physician or institution unless they are relatives of the patient. The health care proxy applies to all situations in which the patient is incapable of making decisions, not just terminal illness. Proxy decisions must be consistent with the patient's previously expressed choices or best interests. However, no additional evidence of the patient's wishes is required if the proxy has been designated in accordance with state requirements. Appointing a health care proxy, supplemented with statements of what life-sustaining treatment the patient would want or refuse in various scenarios, is the best way to provide advance directives.

LIMITATIONS OF ADVANCE DIRECTIVES (4)

Advance Directives Might Not Be Informed

Even after discussions with physicians, only 33% of patients know that patients on a ventilator cannot talk and about one half believe that ventilators are oxygen tanks or that ventilated people are always comatose (17). Similarly, patients have serious misunderstandings about cardiopulmonary resuscitation (CPR). Over one fourth cannot identify any basic characteristics of CPR, such as chest compressions or assisted breathing (17). Only one third know that even if CPR succeeds in restarting the heart a breathing machine is usually needed. Thus, "patients expressed strong preferences about treatments that they did not understand (17)."

Patients also overestimate their prognosis (17,18). In a cohort of patients with metastatic lung or colon cancer, who had a 6-month survival of 45%, most patients were decidedly overoptimistic: 59% believed that their chance of surviving 6 months was greater than 90% (19).

Interpretations of Advance Directives Might Be Problematic

Vague terms. Advance directives often use vague terms such as “heroic” or “extraordinary” care. Physicians are commonly directed to refuse interventions when “the burdens outweigh the benefits of care.” As Chapter 15 discusses, these terms are ambiguous and misleading. In Case 12.1 such vague terms provide little guidance. Did Mrs. A want to decline antibiotics for infection or did she want to decline only more invasive interventions such as CPR and mechanical ventilation? Mrs. A said that she did not want life-sustaining treatment if she became “senile,” but when does “senility” commence? When she can no longer pursue favorite activities? When she sometimes does not recognize family members? Or only when she no longer responds at all? Studies show that patients’ choices in specific scenarios cannot be accurately predicted from their general preferences and goals (20,21).

Application to similar situations. A patient might give advance directives about one situation but develop a different condition. For example, a patient might give directives about dementia but develop a major stroke. Patients differ in how much leeway they want surrogates to take to apply their directive to other circumstances or interventions. In one study 39% of patients wanted their directives to be followed literally, but 31% of patients wanted their surrogates to override their advance directives if their surrogates believed it was best for them (22).

Unrealistic expectations. Physicians sometimes insist on life-sustaining interventions because it is not certain that the patient would not want them. Undue requirements of the patient’s wishes might impose burdensome interventions on patients and make them “prisoners of technology (23).” Even if treatments cannot be foregone on the basis of advance directives, they might be withheld or withdrawn on the basis of substituted judgments or best interests.

Advance Directives Might Conflict with the Patient’s Best Interests

Following the patient’s advance directives might not be in his or her current best interests. For example, surrogates and physicians might wish to override prior refusal of care if a brief intervention is virtually certain to restore the patient to previous health (24).

When providing advance directives, patients make implicit assumptions about their prognosis or situation. However, promising new therapies might become available, other serious medical conditions might develop, a treatment might prove unsuccessful, or a spouse might die. Such developments would make prior directives less pertinent to the current situation.

More fundamentally, the incompetent person might have changed so much since giving advance directives that he or she is essentially a different person from when he or she gave the directives (25,26). In this view, advance directives are not binding. Mrs. A’s brother questions whether her previous statements are still relevant because she has changed so dramatically. On the other hand, many people believe that although Mrs. A is not as alert as she once was, she is in essence still the same person and that her directives should be respected.

Patients Might Change Their Minds

After patients indicate that they would decline interventions, in 21% to 28% of cases they subsequently decide that they would accept the interventions, or at least try them (27,28). Acceptance of life-sustaining interventions is less stable. After patients indicate that they would accept life-sustaining interventions, from 43% to 50% indicate in later interviews that they would decline the intervention. Furthermore, 68% of patients who say they would accept a trial of treatment subsequently say they would decline the intervention (27).

Despite these limitations, advance directives should be encouraged. They promote respect for patients as individuals with unique characters and values. They also encourage discussions of life-sustaining interventions among patients, family members, and physicians.

RATIONALE FOR DISCUSSING ADVANCE DIRECTIVES WITH PATIENTS

Most patients—between 59% and 85% of outpatients—want to talk with their physicians about life-sustaining interventions before a clinical crisis occurs (2,3,6), yet few have done so. When thinking or talking about life-sustaining interventions, most patients feel in control, relieved, or

" or "extraordinary" burdens outweigh the leading. In Case 12.1's for infection or did mechanical ventilation? nile," but when does she sometimes does!? Studies show that r general preferences

s about one situation s about dementia but ates to take to apply atients wanted their tes to override their

nterventions because the patient's wishes of technology (23)." might be withheld or

it best interests. For e if a brief interven-

bout their prognosis her serious medical ise might die. Such m.

since giving advance e gave the directives ons whether her pre- he other hand, many ssence still the same

of cases they subse- (27,28). Acceptance f would accept life-y would decline the of treatment subse-

promote respect for e discussions of life-

ENTS

ir physicians about ave done so. When control, relieved, or

cared for (2). Even patients who feel sad or anxious when thinking about life-sustaining treatment still want to have such conversations (2,6). Among hospitalized patients, between 42% and 81% want to discuss end-of-life decisions with their physicians (29,30). Most patients want physicians to take the initiative in discussing advance directives (2,31). The physician can also help patients understand the usefulness and limitations of advance directives. The federal Patient Self Determination Act is intended to promote discussions about advance directives (32). Hospitals, nursing homes, and health maintenance organizations that participate in Medicaid and Medicare must inform patients about their rights to provide advance directives at the time of admission or enrollment. Institutions must also carry out advance directives and educate their staffs about them. Patients are not required to complete an advance directive.

PROBLEMS WITH DISCUSSIONS ABOUT ADVANCE DIRECTIVES

Currently, discussions between patients and physicians about advance directives are problematic. In one study only 11% of patients who had executed advance directives had discussed them with their physicians (33). Almost all discussions concerned general attitudes and feelings rather than specific interventions (33).

Even when discussions occur, they rarely give patients enough information to make informed decisions (34). Physicians usually pose hypothetical scenarios to patients, but they generally discuss extreme scenarios in which there was little variation in patient preferences. Almost all physicians discuss dire scenarios in which patients are permanently unconscious, will not survive outside an intensive care unit, or are about to die. Virtually no patients want interventions in such dire scenarios. Moreover, physicians often discuss reversible scenarios in which patients are expected to regain their previous health. Almost all patients accept even "heroic" interventions in such reversible scenarios. Thus, discussions of these extreme scenarios provide little guidance. Physicians seldom discuss more difficult—and more common—situations, such as when recovery is unpredictable or the patient has chronic disability after treatment.

Typically, physicians use vague language, asking patients what they would want if they were "very, very sick" or "had something that was very serious." Doctors rarely define such terms or ascertain how patients interpreted them. Physicians commonly discuss specific interventions, usually CPR or mechanical ventilation. However, rarely do physicians attempt to learn what patients know about these interventions. In discussing outcomes, physicians seldom give numerical probabilities of success or mention outcomes other than death and complete recovery.

Physicians rarely elicit patients' values, goals for care, and reasons for choices. Most commonly, physicians determine whether patients wanted specific interventions in scenarios without exploring the reasons for those preferences. Even when reasons are discussed, physicians rarely ask patients to define a poor quality of life or being a burden to their family, which are frequent reasons for refusing interventions.

IMPROVING DISCUSSIONS ABOUT ADVANCE DIRECTIVES

When Should Discussions about Advance Directives Be Initiated?

Physicians should discuss advance directives when it would not be surprising if the patient were to lose decision-making capacity or to die (35). Hence, physicians should target not only patients who are "terminal" or in a downhill course, but also those with serious chronic illness such as congestive heart failure, whose course is not so predictable. Patients usually want discussions to occur earlier than physicians do: earlier in the natural history of disease as well as earlier in the patient-physician relationship (31). If the physician waits until clinical deterioration has already occurred, the patient is often too sick to make informed decisions (36).

In some cultures advance directives might be inappropriate. For example, many traditional Chinese patients believe that giving explicit directives implies that they do not trust their family to make decisions for them (37). Moreover, they might believe that designating a single person to make decisions violates their desire for family decision making. Furthermore, some patients believe that talking about future illness will anger ghosts or spirits, who will then bring about the illness or cause bad luck. Such reluctance to discuss future plans needs to be respected.

TABLE 12-2

Topics to Discuss Regarding Advance Directives

Who should serve as proxy?
 What are the patient's general preferences and values?
 What are the patient's preferences in specific clinical situations?
 How should advance directives be interpreted?
 How do patients want to be treated near the end of life?

Physicians can resolve many problems with advance directives by explicitly addressing the following issues (Table 12-2):

Who Should Serve as Proxy?

Most patients find it easier to discuss the choice of proxy than to discuss preferences regarding care. Straightforward questions might broach the topic: "I ask all my patients with heart disease how they want decisions to be made. Who would you want to make decisions for you in case you are too sick to talk with me directly?" Those who do not wish to discuss these topics can easily demur.

Patients need to select someone whom they trust to make decisions in unforeseen situations. Although patients should provide guidance to their proxies, it is likely that proxies will have to exercise judgment about what patients would want or what is best for them. Patients cannot anticipate what specific decisions and conditions.

What Are the Patient's General Preferences and Values?

Many physicians focus discussions on specific medical decisions, such as Do Not Attempt Resuscitation (DNAR) orders. However, it is premature to discuss particular decisions before understanding patient's concerns and expectations. Often, specific decisions are easier to make after the patient discusses his or her general values and preferences. Open-ended questions help elicit the patient's perspective (38):

- "When you think of serious illness, what concerns you the most?" Alternatively, "When you think of serious illness, what is most important to you?"
- "Sometimes your family might need to make decisions about your medical care. What things would you want them to take into account?" These questions elicit how the patient defines his or her best interests or an acceptable quality of life.
- "Are there conditions under which you would not want life-prolonging interventions?"

What Are the Patient's Preferences in Specific Clinical Situations?

It is unrealistic to try to discuss all future medical situations. The goal of discussions is not to be exhaustive but to elicit informed choices about likely scenarios and to understand what considerations are important to the patient.

Discuss scenarios that are likely to occur (39). Although the PVS has captured public attention, it is very rare. Rather than discussing dire or completely reversible situations, physicians should discuss common scenarios in which the outcome is uncertain and the interventions are burdensome (17).

Physicians need to describe interventions and their likely outcomes. For CPR, patients need to know about chest compressions, artificial respirations, electroshock, the low likelihood of survival after CPR, and the possibility of neurological compromise (*see* Chapter 17). For mechanical ventilation, patients need to understand that they will have a tube in their throat, will not be able to speak, and will probably need sedation.

For patients
 respiratory failure
 on life-prolonging

For patient
 advanced disease
 likelihood, magnitude

With elderly
 would the patient
 a feeding tube
 or severe stroke

Correct use
 a woman with
 done. In such
 ended questions
 spreads like a
 impossible (40)
 breathing machine

Use of specific
 four clinical
 are useful when
 fully informed
 fully appreciate

How Should
 Because advance
 patient would
 Physicians
 mean by "no
 Physicians
 their directive
 in their best

How Do Patients
 A recent advance
 that "I love the
 not what they
 finally to say
 ending closer

CONTINUE

Physicians should
 situation, patient
 approval of the
 wife and the
 advance directive

Recommend
 Physicians should
 patients to consult
 these courts

Document the
 The physician
 consequences
 various situations

For patients with coronary artery disease, cardiopulmonary arrest, cardiogenic shock, and respiratory failure from pulmonary edema should be discussed. What limits would the patient place on life-prolonging interventions if prolonged ventilatory or multisystem failure develops?

For patients with cancer, the physician should discuss altered mental status and sepsis in advanced disease. What types of intervention would the patient be willing to accept? For what likelihood, magnitude, and duration of improvement?

With elderly patients, physicians should discuss severe dementia and stroke. In these situations, would the patient want infections treated with antibiotics or intensive care? Would the patient want a feeding tube if he or she could not swallow food? How would the patient define severe dementia or severe stroke?

Correct unrealistic expectations. Patients might have unrealistic expectations. For example, a woman with lung cancer metastatic to liver and bone might indicate that she wants everything done. In such cases physicians should elicit expectations, concerns, and emotions, using open-ended questions. The physician could say, "What do you think happens to patients whose cancer spreads like that?" "Wish statements" might help physicians explain that the patient's goals are impossible (40). "I wish that were the case. Unfortunately when cancer has spread that much, even breathing machines don't help patients live much longer."

Use of specific checklists. The Medical Directive is a checklist of 12 interventions in each of four clinical scenarios: terminal illness, dementia, PVS, and coma (41). Such specific directives are useful when the patient and physician have discussed these situations and the patient has made truly informed decisions, but they might be misleading if the patient expresses choices without fully appreciating the issues and deliberating about them.

How Should Advance Directives Be Interpreted?

Because advance directives cannot cover all contingencies, it is important to understand how the patient would want the surrogate and physician to interpret his or her preferences.

Physicians need to ask patients to clarify ambiguous statements: "Can you tell me what you mean by 'no heroic treatment'?"

Physicians should also ask patients how much leeway they would allow surrogates to interpret their directives, extrapolate them to unforeseen situations, or override their directives if it seemed in their best interests (22).

How Do Patients Want to Be Treated near the End of Life?

A recent advance directive form enables patients to indicate that they want their families to know that "I love them," "I wish to be forgiven for the times I might have hurt them," and "I forgive them for what they have done to me (42)." In addition, patients can fill out what they would like their family to say if anyone asks how they want to be remembered. This directive shifts the focus to finding closure at the end of life.

CONTINUE DISCUSSIONS OVER TIME

Physicians should not expect to understand the patient's preferences after a single conversation. In addition, patients' choices and values might change as their illness, their life situation, or their appraisal of their situation changes. If patients change their mind, they should tell both the surrogate and the physician, destroy all copies of written advance directives, and complete a new advance directive.

Recommend Written Directives

Physicians should tell patients about the advantages of written advance directives and encourage patients to complete them. This is particularly important in states such as New York and Missouri, whose courts have rejected most oral directives.

Document Discussions in the Medical Record

The physician's note should describe the patient's decision-making capacity, appreciation of the consequences of the patient's choices, and his or her specific preferences about interventions in various situations. It is not necessary for the patient to sign the record.

SUBSTITUTED JUDGMENT

Clear and specific advance directives should be respected, but often patients have given only general directives or no indication of their preferences, as in the following case.

CASE 12.2 Disagreements over substituted judgment.

Mr. S, a 76-year-old widower, suffers a massive stroke and aphasia. Two weeks later he still has paralysis of his right arm and leg. He does not respond consistently to simple requests or questions but sometimes smiles when his hand is held. He develops pneumonia.

Throughout his life he had been reluctant to see physicians and did not regularly take prescribed medications to lower his cholesterol. He loved to take walks and work in his garden. When his wife died of a sudden heart attack, he said, "Death isn't the enemy. She wanted to be active and healthy to the end, and the good Lord granted her wish." He was a proud and independent man who was reluctant to accept help from others. He has given no oral or written advance directives. His son and daughter believe Mr. S would refuse antibiotics. "He disliked being dependent on others and would hate being in a nursing home. In his condition he can't do any of the things he loved in life."

In the absence of clear and specific advance directives, surrogates should try to construct the decision that the patient would make under the circumstances, taking into account all that is known about the patient. The surrogate might imagine that the patient miraculously regains decision-making capacity. What care would the patient choose under the circumstances?

Reconstructing patients' choices is ethically justified because it respects their individuality to the extent that this is possible (26). Patients usually trust a family member or other surrogate to make the best decision possible under circumstances that were not foreseen (1).

PROBLEMS WITH SUBSTITUTED JUDGMENT

Inconsistency

Reasonable people acting in good faith may disagree over what the patient would want. For example, his sister might believe that Mr. S would want antibiotics. "He's been a fighter all his life and never gave up." She recalled that as a young man, Mr. S had overcome tremendous odds to come to America and get a college education.

Inaccuracy

Neither family members nor physicians can accurately state a competent patient's choices regarding future life-sustaining treatment (43–46). In one study only 68% of family members correctly stated a competent patient's preferences for CPR if he or she developed dementia and only 59% of physicians were able to do so (43). This level of agreement between proxies and patients would be expected by chance alone. Surrogates' statements about patients' preferences are closer to what *they* would want in the situation than to what the patient actually wants (47). Even an intensive intervention that facilitated discussions between the patient and proxy about the patient's wishes for end-of-life care failed to increase the level of agreement (48).

Questionable Considerations

Competent patients might not want to be a burden or might want to spare the family the expenses and stress of terminal care (1). It seems reasonable for surrogates to consider these factors when the patient himself has already done so, but it might be self-serving for surrogates to consider such factors when patients have not stated their importance (49). Family members might confound what they would want with what the patient would want.

Unavoidable Speculation

Substituted judgments are inherently less certain than advance directives (50–52). Mr. S's comments about his wife do not necessarily express his own desires for medical care. Even though he could no longer take walks and read, he might adapt to his illness and find life worthwhile. Many independent people learn to accept disabilities and assistance from others. In Case 12.2

have given only gen-

ter he still has paraly-
r questions but some-

ularly take prescribed
n. When his wife died
ive and healthy to the
an who was reluctant
His son and daughter
d would hate being in

to construct the deci-
ll that is known about
uns decision-making

their individuality to
or other surrogate to
e).

would want. For exam-
ighter all his life and
dous odds to come to

ent's choices regard-
y members correctly
ntia and only 59% of
nd patients would be
s are closer to what
's). Even an intensive
the patient's wishes

family the expenses
r these factors when
ates to consider such
might confound what

0-52). Mr. S's com-
al care. Even though
ind life worthwhile.
others. In Case 12.2

the children's reasoning is unconvincing when applied to the converse situation. If a patient had seen physicians regularly, taken medications faithfully, and pursued no hobbies, it would be illogic to infer that he wanted all life-sustaining interventions in this situation.

Conflicts with the Patient's Best Interests

In unusual cases substituted judgments might lead to decisions that contradict the patient's current best interests. For example, family members might say that a mildly demented patient would not want life-prolonging interventions, even though that patient still enjoys activities such as listening to music or playing with grandchildren. Although it would be appropriate to withhold treatment in this situation on the basis of a clear and specific advance directive, it is problematic to do so as a substituted judgment.

Despite the potential pitfalls of substituted judgments, they are desirable because they respect the patient's individuality as a person with unique values and preferences (26).

BEST INTERESTS

For some patients who have not given advance directives, a substituted judgment would be so speculative that it is more honest for the surrogate and physician to base decisions on what they believe is best for the patient (53). A consensus of medical ethicists and clinicians supports decisions based on the patient's best interests (50,54,55). Such decisions are justified by the ethical guideline of beneficence: Physicians must act for the patient's well-being and must weigh the benefits and burdens of interventions for the patient.

Some scholars advocate a best-interests standard because statements previously made by an incapacitated patient in a vastly different situation might not be relevant (25,50,53). For example, these writers believe that preferences expressed by a young, healthy person should not carry much weight years later when that person is severely demented. Indeed, some writers have suggested that the patient with severe dementia should be considered a different person from the one who provided the advance directives, with different values and preferences. In this view previous directives are irrelevant to current decisions.

PROBLEMS WITH BEST INTERESTS

Different people might disagree over what is best for a patient. Disagreements might involve the goals of care, the assessment of the benefits and burdens of an intervention, or the evaluation of the patient's quality of life. Judgments about quality of life are particularly controversial if they are made by a surrogate rather than by the patient because other people underestimate patients' quality of life. Chapter 4 discusses these issues in more detail.

Some surrogates request painful interventions that will only prolong the patient's life a few days. Surrogates might believe that suffering serves a spiritual purpose or that biological life should be prolonged even if the interventions required are very burdensome. Decisions based on such beliefs need to be scrutinized carefully (56). Did the patient hold such views, as opposed to the surrogate? Did the patient say explicitly that he or she would accept painful interventions or decline palliative relief? Many patients who believe their illness serves a spiritual purpose will still decline burdensome interventions. Caregivers might believe that they are causing the patient to suffer if they do not provide standard palliative care (56,57). The ethical guideline of nonmaleficence allows health care workers to refrain from interventions that cause significant suffering and prolong the patient's life for only a few hours or days (see Chapter 14) (56).

Incompetent patients who have not given advance directives and have no surrogates often pose difficult cases. Some doctors mistakenly believe all life-sustaining interventions that are technically feasible should be provided to such patients unless they are futile. However, insisting on life-sustaining interventions because it is not certain that the patient would not want them might impose burdensome interventions on patients and make them "prisoners of technology (23)." To safeguard against bias, procedures such as consultation with another physician or with the hospital ethics committee often are useful. Despite problems with best interests, it is an acceptable reason to forego such interventions in such situations.

In summary, advance directives are the preferred way to make decisions for patients who lack decision-making capacity. Advance directives might be oral statements or documents such as living wills or durable powers of attorney for health care. The most comprehensive and flexible advance directives both appoint a proxy and express choices about treatments. In discussions with patients, physicians can ensure that advance directives are informed. In the absence of clear advance directives, surrogates should try to make substituted judgments. If the patient's values and preferences are not known, decisions need to be based on the patient's best interests. In making these decisions, physicians need to guard against two types of errors: withholding treatments that might be beneficial or continuing treatments that the patient would not want.

REFERENCES

1. Singer PA, Martin DK, Lavery JV, et al. Reconceptualizing advance care planning from the patient's perspective. *Arch Intern Med* 1998;158(8):879-884.
2. Lo B, McLeod G, Saika G. Patient attitudes towards discussing life-sustaining treatment. *Arch Intern Med* 1986;146:1613-1615.
3. Emanuel LL, Barry MJ, Stoeckle JD, et al. Advance directives for medical care—a case for greater use. *N Engl J Med* 1991;324:889-895.
4. Lo B, Steinbrook RL. Resuscitating advance directives. *Arch Intern Med* 2004;164:1501-1506.
5. Lo B, Rouse F, Dornbrand L. Family decision-making on trial: who decides for incompetent patients? *N Engl J Med* 1990;322:1228-1231.
6. Steinbrook R, Lo B, Moulton J, et al. Preferences of homosexual men with AIDS for life-sustaining treatment. *N Engl J Med* 1986;314:457-460.
7. Meisel A. *The right to die*, 2nd ed. New York: John Wiley and Sons, 1995.
8. Sabatino CS. The legal and functional status of the medical proxy: suggestions for statutory reform. *J Law Med Ethics* 1999;27(1):46-51.
9. Rubin SM, Strull WM, Fialkow MF, et al. Increasing completion of the durable power of attorney for health care: a randomized controlled trial. *JAMA* 1994;271:209-212.
10. Sulmasy DP, Song KY, Marx ES, et al. Strategies to promote the use of advance directives in a residency outpatient practice. *J Gen Intern Med* 1996;11:657-663.
11. Meier DE, Fuss BR, O'Rourke D, et al. Marked improvement in recognition and completion of health care proxies. *Arch Intern Med* 1996;156:1227-1232.
12. Teno J, Lynn J, Wenger N, et al. Advance directives for seriously ill hospitalized patients: effectiveness with the patient self-determination act and the SUPPORT intervention. *J Am Geriatr Soc* 1997;45(4):500-507.
13. Bradley EH, Wetle T, Horwitz SM. The patient self-determination act and advance directive completion in nursing homes. *Arch Fam Med* 1998;7(5):417-423.
14. Orentlicher D. Advance medical directives. *JAMA* 1991;263:2365-2367.
15. Annas GJ. The health care proxy and the living will. *N Engl J Med* 1991;324:1210-1213.
16. Steinbrook R, Lo B. Decision making for incompetent patients by designated proxy. *N Engl J Med* 1984;310:1598-1601.
17. Fischer GS, Tulskey JA, Rose MR, et al. Patient knowledge and physician predications of treatment preferences after discussions of advance directives. *J Gen Intern Med* 1998;13:447-454.
18. Murphy DJ, Burrows D, Santilli S, et al. The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation. *N Engl J Med* 1994;330:545-549.
19. Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA* 1998;279:1709-1714.
20. Schneiderman LJ, Kronick R, Kaplan RM, et al. Effects of offering advance directives on medical treatments and costs. *Ann Intern Med* 1992;117:599-606.
21. Fischer GS, Alpert HR, Stoeckle JD, et al. Can goals of care be used to predict intervention preferences in an advance directive? *Arch Intern Med* 1997;157:810-807.
22. Sehgal A, Galbraith A, Chesney M, et al. How strictly do dialysis patients want their advance directives followed? *JAMA* 1992;267:59-63.
23. Angell M. Prisoners of technology: the case of Nancy Cruzan. *N Engl J Med* 1990;322:1226-1228.
24. Danis M, Southerland LI, Garrett JM, et al. A prospective study of advance directives for life-sustaining care. *N Engl J Med* 1991;324:882-888.
25. Dresser RS, Robertson JA. Quality of life and non-treatment decisions for incompetent patients: a critique of the orthodox approach. *Law, Med Health Care* 1989;17:234-244.
26. Blustein J. Choosing for others as continuing a life story: the problem of personal identity revisited. *J Law Med Ethics* 1999;27(1):13-19.
27. Emanuel LL, Emanuel EJ, Stoeckle JD, et al. Advance directives. Stability of patients' treatment choices. *Arch Intern Med* 1994;154(2):209-217.
28. Danis M, Garrett J, Harris R, et al. Stability of choices about life-sustaining treatments. *Ann Intern Med* 1994;120:567-573.
29. Reilly BM, Magnussen CR, Ross J, et al. Can we talk? Inpatient discussions about advance directives in a community hospital. Attending physicians' attitudes, their inpatients' wishes, and reported experience. *Arch Intern Med* 1994;154(20):2299-2308.

patients who lack
ments such as liv-
isive and flexible
discussions with
absence of clear
tient's values and
erests. In making
ig treatments that

atient's perspective.

it. *Arch Intern Med*

reater use. *N Engl J*

06.

t patients? *N Engl J*

sustaining treatment.

reform. *J Law Med*

ney for health care:

a residency outpa-

of health care prox-

ectiveness with the
00-507.

ompletion in nurs-

' *J Med* 1984;310:

ment preferences

ients' preferences

agnosis and their

cal treatments and

preferences in an

ectives followed?

228.

-sustaining care.

: a critique of the

sited. *J Law Med*

nt choices. *Arch*

tern Med 1994;

ectives in a com-
nce. *Arch Intern*

30. Hoffman JC, Wenger NS, Davis RH, et al. Patient preferences for communication with physicians about end-of-life decisions. *Ann Intern Med* 1997;127:1-12.
31. Johnston SC, Pfeifer MP, McNutt R, End of Life Study Group. The discussion about advance directives. Patient and physician opinions regarding when and how it should be conducted. *Arch Intern Med* 1995;155(10):1025-1030.
32. Omnibus Budget Reconciliation Act of 1990. Pub. L. No. 101-508 §§4206,4751.
33. Virmani J, Schneiderman LJ, Kaplan RM. Relationship of advance directives to physician-patient communication. *Arch Intern Med* 1994;154:909-913.
34. Tulskey JA, Fischer GS, Rose MR, et al. Opening the black box: how do physicians communicate about advance directives. *Ann Intern Med* 1998;129:441-449.
35. Lynn J, Schuster JL. *Improving care for the end of life: a sourcebook for health care managers and clinicians*. New York: Oxford University Press, 1999.
36. Council on Ethical and Judicial Affairs AMA. Guidelines for the appropriate use of do-not-resuscitate orders. *JAMA* 1991;265:1868-1871.
37. Bowman KW, Singer PA. Chinese seniors' perspective on end-of-life decisions. *Soc Sci Med* 2001;53:455-464.
38. Lo B, Snyder L, Sox H. Care at the end of life: guiding practice where there are no easy answers. *Ann Intern Med* 1999;130:772-774.
39. Singer PA. Disease-specific advance directives. *Lancet* 1994;344(8922):594-596.
40. Back AL, Arnold RM, Quill TE. Hope for the best, and prepare for the worst. *Ann Intern Med* 2003;138(5):439-443.
41. Emanuel LL, Emanuel EJ. The medical directive. *JAMA* 1989;261(22):3288-3293.
42. Five Wishes. Available at: www.agingwithdignity.org. Accessed November 13, 2002.
43. Seckler AB, Meier DB, Mulvihill M, et al. Substituted judgment: how accurate are proxy predictions? *Ann Intern Med* 1991;115:92-98.
44. Emanuel EJ, Emanuel LL. Proxy decision making for incompetent patients: an ethical and empirical analysis. *JAMA* 1992;267:2067-2071.
45. Suhl J, Simons P, Reedy T, et al. Myth of substituted judgment: surrogate decision making regarding life support is unreliable. *Arch Intern Med* 1994;154:90-96.
46. Sulmasy DP, Terry PB, Weisman CS, et al. The accuracy of substituted judgments in patients with terminal diagnoses. *Ann Intern Med* 1998;128:621-629.
47. Fagerlin A, Ditto PH, Danks JH, et al. Projection in surrogate decisions about life-sustaining medical treatments. *Health Psychol* 2001;20(3):166-175.
48. Ditto PH, Danks JH, Smucker WD, et al. Advance directives as acts of communication: a randomized controlled trial. *Arch Intern Med* 2001;161:421-430.
49. Lo B. Caring for the incompetent patient: is there a doctor in the house? *Law Med Health Care* 1990;17:214-220.
50. Buchanan AE, Brock DW. *Deciding for others*. Cambridge: Cambridge University Press, 1989.
51. Annas GJ. Quality of life in the courts: Earle Spring in fantasyland. *Hastings Cent Rep* 1980;10:9-10.
52. Annas GJ. The case of Mary Hier: when substituted judgment becomes sleight of hand. *Hastings Cent Rep* 1984;14:23-25.
53. Rhoden N. How should we view the incompetent? *Law Med Health Care* 1989;17:264-268.
54. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to forego life-sustaining treatment*. Washington: U.S. Government Printing Office, 1983.
55. Meisel A. *The right to die*. New York: John Wiley and Sons, 1989.
56. Alpers A, Lo B. Avoiding family feuds: responding to surrogates' demands for life-sustaining treatment. *J Law Med Ethics* 1999;27:74-80.
57. Braithwaite S, Thomasma DC. New guidelines on foregoing life-sustaining treatment in incompetent patients: an anti-cruelty policy. *Ann Intern Med* 1986;104:711-715.

ANNOTATED BIBLIOGRAPHY

1. Lo B, Steinbrook RL. Resuscitating advance directives. *Arch Intern Med* 2004;164:1501-1506.
Analyzes limitations of advance directives and argues that emphasis should be on appointing a proxy whom the patient trusts to make decisions.
2. Arnold RM, Kellum J. Moral justifications for surrogate decision making in the intensive care unit: implications and limitations. *Crit Care Med* 2003;31:S347-S353.
Practical analysis of different standards for decisions regarding incompetent patients.
3. Buchanan AE, Brock DW. *Deciding for others*. Cambridge: Cambridge University Press, 1989.
Thoughtful book on making decisions for patients who lack the capacity to make informed decisions.
4. Tulskey JA, Fischer GS, Rose MR. Opening the black box: how do physicians communicate about advance directives? *Ann Intern Med* 1998;129:441-449.
Well-designed study elucidating problems that occur when physicians discuss advance directives with patients.
5. Emanuel EJ, Emanuel LL. Proxy decision making for incompetent patients: an ethical and empirical analysis. *JAMA* 1992;267:2067-2071.
Summarizes data showing how families and physicians might not be able to state patients' preferences accurately.
6. <http://www.partnershipforcaring.org/HomePage> Website to download state advance directive forms from the Internet.

Surrogate Decision Making

When patients lack decision-making capacity, physicians turn to surrogates to make decisions on their behalf. Traditionally, family members serve as surrogate decision-makers for such patients. Note that this book uses the term “surrogate” for anyone who makes decisions for a patient who lacks decision-making capacity and reserves the term “proxy” for a surrogate appointed by the patient. This distinction is most helpful when there is disagreement over who should make decisions for the patient. Proxies designated by the patient have a stronger ethical claim to make decisions for such patients than relatives. Also, in some states proxies designated by the patient have better legal standing, particularly if the patient has completed a formal legal document designating them. Chapter 12 discusses the related issue of what standards should be used in making decisions for patients who lack decision-making capacity.

CASE 13.1 Disagreement between family members.

Mrs. R is a 72-year-old widow with severe Alzheimer disease. She does not recognize her family but often smiles when someone holds her hand or gives her a hug. She lives with her sister, who provides help with all activities of daily living together with an attendant. Mrs. R develops pneumonia. She had never indicated what she would want in such a situation or whom she would want to make decisions for her. Her sister believes that Mrs. R would not want her life prolonged in this condition because she prized her independence and asks the physician to withhold antibiotics. Mrs. R's only child is a son who visits once or twice a year. He is outraged at this request. He asserts, "Life is sacred; it's God's gift. We can't just snuff it out."

Because Mrs. R had given no advance directives, a surrogate needs to make decisions on care. Both the sister and the son desire to act as Mrs. R's surrogate. The sister asserts priority because she cared for Mrs. R and has been close to her sister most of her life, yet the son has closer ties of kinship. What justifies selecting one surrogate over the other?

WHO SHOULD SERVE AS SURROGATE?

Among potential surrogates there is a hierarchy that physicians should keep in mind. However, decisions are often best made by consensus rather than by giving one potential surrogate unilateral power.

COURT-APPOINTED GUARDIANS

The courts have legal authority to declare a patient incompetent and to appoint a guardian to make medical decisions for the patient. The legal system offers procedural safeguards, such as notice to all parties, the right to call and cross-examine witnesses, impartial judges, explicit justification for

decisions, and an appeals process. However, involving the courts routinely in decisions has serious drawbacks (1,2). First, the courts intrude on highly personal and private issues. The adversarial judicial system might polarize families and physicians rather than foster a mutually acceptable decision. Second, guardianship hearings are usually superficial, and courts do not monitor guardians' decisions (3). Finally, intolerable delays would occur if the courts were frequently involved in decisions on life-sustaining treatment. As one court decision declared, "Courts are not the proper place to resolve the agonizing personal problems that underlie these cases. Our legal system cannot replace the more intimate struggle that must be borne by the patient, those caring for the patient, and those who care about the patient (4)." Court-appointed guardians have legal priority over other potential surrogates. However, physicians and hospitals should involve the courts only as a last resort, when disputes cannot be resolved in a clinical setting.

SURROGATES SELECTED BY PATIENTS

As Chapter 12 discusses, all states have legal procedures for competent patients to appoint a health care proxy (5,6). Generally, the patient must complete a form and have it witnessed or notarized. Many patients find it easier to select who should act as proxy rather than anticipate what they would want in future scenarios. Appointing a proxy might prevent disputes.

In some cases the patient indicates the selection of a surrogate informally but does not complete a legal document appointing the person. If the surrogate and close relatives disagree over plans for care, the physician might then face a conflict between what is ethically appropriate and what is legally protected. Ethically speaking, the person whom the patient wanted to serve as surrogate should have priority. Legally, however, persons might have no standing to make decisions. The physician should try to persuade the family to respect the patient's choice of proxy.

FAMILY MEMBERS

Decisions by families of patients who lack decision-making capacity are standard medical practice (7,8). There are compelling ethical justifications for family decision making (9).

Most People Want Family Members to Serve as Surrogates

A public opinion poll found that 30% of respondents wanted their families to make medical decisions for them if they became incapacitated. An additional 53% wanted their family to make decisions together with their physicians (10). Only 3% of respondents wanted the courts to decide. Patients trust family members to do their best under circumstances that might not be foreseen (11).

Family Members Often Know What the Patient Would Want

Because family members generally have close relationships with patients, they are more likely than other people to have discussed life-sustaining interventions with patients.

Family Members Are Presumed to Act in the Patient's Best Interests

Ties of kinship and affection generally lead family members to care about the patient, deliberate carefully, and do what is best for the patient rather than what is best for themselves (9). Strong social, cultural, and religious norms encourage family members to subordinate their own interests for the sake of relatives in need.

The term "family" should be interpreted in light of demographic facts, such as the large number of unmarried couples living together. Ethically, the crucial issue is not the relationship's legal status but whether it is reasonable to presume that the partner will act in the patient's best interests.

Decision Making by the Family as a Group

For many families the idea of singling out one person as a surrogate might seem to disrespect the family as a whole. Family connections have both ethical and practical significance. Proponents of an ethics of care (see Chapter 1) have argued that more attention should be paid to how decisions affect various relationships and that families should have a stronger voice in health care decisions (12,13). In this view relationships among family members will survive after the patient's death.

These relationships deserve respect, and physicians should support attempts to maintain family harmony. From a pragmatic viewpoint, many proxies are reluctant to contradict the views of close relatives. They might feel torn between what they think is best for the patient and what other family members want to do (14).

NO FAMILY MEMBERS AVAILABLE

Decisions are most difficult when patients with impaired decision-making capacity have no advance directives and no family members. In some cases a friend might be an appropriate surrogate. If the friend has an emotional bond with the patient, it is plausible to presume that the friend will act in the patient's best interests (15).

If no one is available as surrogate, it is appropriate for physicians to make decisions on the basis of what they believe is in the patient's best interests. Physicians do not need to administer burdensome interventions that offer little prospect of benefit simply because there is no surrogate to decline them on behalf of the patient. In this situation physicians may forego interventions that they do not consider to be in the patient's best interests. When there is no surrogate, it is advisable for physicians to consult with the hospital ethics committee or another physician. Simply explaining one's reasoning to another person can clarify thinking, identify unwarranted assumptions and unconvincing arguments, and suggest new options for care.

LEGAL ISSUES REGARDING SURROGATE DECISION MAKING

Many states allow relatives to refuse interventions on behalf of such patients, even in the absence of advance directives (5,6,8).

In 31 states legislation specifies which relatives have priority to act as surrogates for incapacitated patients who have not appointed a proxy (6,16,17). Generally, the patient's spouse takes priority over adult children, followed by parents and more distant relatives. Such laws, however, might lead to ethically troubling results, such as favoring the distant son in Case 13.1 over the sister who is closer to the patient. These laws might also be problematic when a spouse is estranged but not legally divorced.

PROBLEMS WITH SURROGATE DECISION MAKING

The physician should serve as the patient's advocate if the surrogate's decision conflicts with the patient's previous statements or best interests.

EMOTIONAL BARRIERS TO DECISIONS

Surrogates commonly find it difficult to make decisions because of emotional stress, such as sadness or denial. Surrogates might also feel guilty over not doing everything for the patient or over "pulling the plug."

DECISIONS INCONSISTENT WITH THE PATIENT'S PREFERENCES OR VALUES

Some surrogates might impose their own values on the patient rather than respect the patient's choices and values. In Case 13.1 the son is basing decisions on religious beliefs about the sanctity of life. When patients themselves hold such views, they are followed out of respect for patient autonomy (see Chapter 4). Thus, the physician needs to inquire whether the patient herself held such religious views.

CONFLICTS OF INTEREST

In some cases relatives might promote their own interests, not the patient's. Unscrupulous family members might try to gain control of an inheritance or a pension. When it comes to the basis for their decisions, surrogates are given less leeway than competent patients. For example, patients

attempts to maintain family harmony and to respect the views of close friends and what other family members think.

Decision-making capacity have no legal authority to be an appropriate surrogate. Do not presume that the friend or family member who is closest to the patient is the best surrogate.

Make decisions on the basis of the patient's known or inferred preferences. If there is no surrogate to make decisions, there is no surrogate to forego interventions that the patient would not want. It is advisable to consult with a physician. Simply explaining the patient's wishes and assumptions and

LEG

ents, even in the absence of a surrogate.

For surrogates for incapacitated patients, the patient's spouse takes priority. Such laws, however, may vary. In Case 13.1 over the sister, a spouse is estranged.

Decision conflicts with the patient's wishes.

Emotional stress, such as sadness or grief for the patient or over the decision.

ES

How can we respect the patient's beliefs about the sanctity of life? Out of respect for patient autonomy, the patient herself held the decision.

It's. Unscrupulous family members may use it comes to the basis for decision. For example, patients

may forego interventions in order to spare family members emotional distress or to preserve an inheritance for children. Such refusals are heeded in order to respect patient autonomy. However, as Chapter 12 discusses, claims by surrogates that the patient would refuse beneficial interventions for these reasons might be self-serving and need to be scrutinized (18).

Family members cannot be expected to ignore their own needs and interests. Caring for a relative with serious chronic illness can cause emotional distress, fatigue, financial burdens, or conflicts with other responsibilities (19). Most family members subordinate their interests to those of the patient and make considerable sacrifices (20). Physicians should not be overly suspicious about surrogates. Respecting close family relationships is an important social value, and physicians should support families who are trying to deal with difficult situations as best as they can. Simply making sacrifices to care for a relative or being mentioned in a will is not a conflict of interests.

DISAGREEMENTS AMONG POTENTIAL SURROGATES

Case 13.1 illustrates how family members might disagree over decisions. Some physicians withhold interventions only when all family members agree. However, giving every relative a veto might impose interventions that are not in the patient's best interests. Furthermore, it is problematic to give distant or estranged relatives a voice equal to that of those closest to the patient. Realistically, physicians often make decisions with family consensus rather than unanimity. Relatives are often willing to accept a decision made by the rest of the family, even though they would have decided differently themselves.

IMPROVING SURROGATE DECISION MAKING

After sufficient discussions, physicians and surrogates agree on decisions about life-sustaining interventions in almost all cases (21). Chapter 15 gives detailed suggestions for reaching agreement. The following additional recommendations refer specifically to surrogate decision making (Table 13-1).

DISCUSS THE DECISION-MAKING PROCESS

A family meeting can help relatives understand and accept the medical situation (22). The hospital ethics committee might be able to facilitate such discussions. Physicians should acknowledge that decisions are difficult and that people with good intentions might disagree. Doctors can help families clarify their role and can accommodate their grief (23). Physicians should remind everybody that decisions should be based on the patient's preferences and values, not on what surrogates or doctors would choose for themselves.

GIVE A RECOMMENDATION

Physicians should not merely list options and leave it to family members to decide. Doctors should make a recommendation on the basis of what is known about the patient's preferences and values. Recommendations are particularly important when family members disagree or are overwhelmed by guilt or grief.

TABLE 13-1

Suggestions for Improving Surrogate Decision Making

1. Discuss the decision-making process.
2. Give a recommendation.
3. Get help from other health care workers.

GET HELP FROM OTHER HEALTH CARE WORKERS

A nurse, social worker, or chaplain can often help the family accept the medical situation and work through past antagonisms with the patient or among themselves. Furthermore, such persons might provide valuable emotional support to family members.

In summary, surrogates should know the incapacitated patient's preferences, be willing to respect them, and act in the patient's best interests. The patient's own choice of surrogate should be respected. In most cases the standard clinical practice of family decision making is ethically appropriate. When family members disagree, physicians should make efforts to resolve conflicts and achieve consensus.

REFERENCES

1. Meisel A. *The right to die*. New York: John Wiley and Sons, 1989:145–169.
2. Lo B, Rouse F, Dornbrand L. Family decision-making on trial: who decides for incompetent patients? *N Engl J Med* 1990;322:1228–1231.
3. Bulcroft K, Kielkopf MR, Tripp K. Elderly wards and their legal guardians: analysis of county probate records in Ohio and Washington. *Gerontologist* 1991;31:156–164.
4. In re Jobes. 529 A. 2d 434 (N.J. 1987).
5. Sabatino CS. The legal and functional status of the medical proxy: suggestions for statutory reform. *J Law Med Ethics* 1999;27(1):46–51.
6. Lo B, Steinbrook RL. Resuscitating advance directives. *Arch Intern Med* 2004;164:1501–1506.
7. *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Deciding to forego life-sustaining treatment*. Washington: U.S. Government Printing Office, 1983.
8. Meisel A. *The right to die*, 2nd ed. New York: John Wiley and Sons, 1995.
9. Arnold RM, Kellum J. Moral justifications for surrogate decision making in the intensive care unit: implications and limitations. *Crit Care Med* 2003;31(5 Suppl):S347–S353.
10. Blendon RJ, Szalay US, Knox RA. Should physicians aid their patients in dying? The public perspective. *JAMA* 1992;267:2658–2662.
11. Singer PA, Martin DK, Lavery JV, et al. Reconceptualizing advance care planning from the patient's perspective. *Arch Intern Med* 1998;158(8):879–884.
12. Jecker N. The role of intimate others in medical decision making. *Gerontologist* 1990;30(1):65–71.
13. Hardwig J. What about the family? *Hastings Cent Rep* 1990;20(2):5–10.
14. Alpers A, Lo B. Avoiding family feuds: responding to surrogates' demands for life-sustaining treatment. *J Law Med Ethics* 1999;27:74–80.
15. Veatch RM. An ethical framework for terminal care decisions. *J Am Geriatr Soc* 1984;32:665–669.
16. Menikoff JA, Sachs GA, Siegler M. Beyond advance directives: health care surrogate laws. *N Engl J Med* 1992;322:1165–1169.
17. American Bar Association. Surrogate consent in the absence of an advance directive, July 1, 2001. <http://www.abanet.org/elderly/update.html>. Accessed May 20, 2002.
18. Lo B. Caring for the incompetent patient: is there a doctor in the house? *Law Med Health Care* 1989;17:214–220.
19. Covinsky KE, Landefeld CS, Teno J, et al. Is economic hardship on the families of the seriously ill associated with patient and surrogate care preferences? *Arch Intern Med* 1996;156(15):1737–1741.
20. Covinsky KE, Goldman L, Cook FS, et al. The impact of serious illness on patients' families. *JAMA* 1994;272:1839–1844.
21. Prendergast TJ, Luce JM. Increasing incidence of withholding and withdrawal of life support from the critically ill. *Am Rev Resp Dis Crit Care Med* 1997;155:15–20.
22. Way J, Back AL, Curtis JR. Withdrawing life support and resolution of conflict with families. *Br Med J* 2002;325(7376):1342–1345.
23. Tilden VP, Tolle SW, Garland MJ, et al. Decisions about life-sustaining treatment: impact of physicians' behaviors on the family. *Arch Intern Med* 1995;155:633–638.

ANNOTATED BIBLIOGRAPHY

1. Lo B, Rouse F, Dornbrand L. Family decision making on trial: who decides for incompetent patients? *N Engl J Med* 1990;322:1228–1231.
Argues that families should be presumed to be appropriate decision-makers for patients who lack decision-making capacity.
2. Buchanan AE, Brock DW. *Deciding for others*. Cambridge: Cambridge University Press, 1989.
Detailed ethical analysis of surrogate decision making.
3. Sabatino CS. The legal and functional status of the medical proxy: suggestions for statutory reform. *J Law Med Ethics* 1999;27:46–51.
Recent analysis of state laws regarding surrogate decision making.
4. Arnold RM, Kellum J. Moral justifications for surrogate decision making in the intensive care unit: implications and limitations. *Crit Care Med* 2003;31:S347–S353.
Clear and thoughtful review of surrogate decision making.

medical situation and work more, such persons might

ances, be willing to respect surrogate should be respected. ethically appropriate. When interests and achieve consensus.

competent patients? *N Engl J*

s of county probate records in

statutory reform. *J Law Med*

1501-1506.
Legal and Behavioral Research.
Office, 1983.

intensive care unit: implications

The public perspective. *JAMA*

from the patient's perspective.

90:30(1):65-71.

-sustaining treatment. *J Law*

84:32:665-669.

the laws. *N Engl J Med* 1992;

the directive, July 1, 2001.

Health Care 1989;17:214-220.
of the seriously ill associated
741.

of families. *JAMA* 1994;272:

the support from the critically

with families. *Br Med J*

impact of physicians' behav-

competent patients? *N Engl J*

s who lack decision-making

ness, 1989.

statutory reform. *J Law Med*

intensive care unit: implications

Persistent Disagreements over Care

Disagreements over life-sustaining interventions are common. According to one study, staff and family disagreed in 48% of intensive care unit (ICU) cases (1). Although disagreements are resolved in almost all cases (2,3), in a few cases sharp disagreements persist. This chapter discusses cases in which either physicians or patients or their surrogates insist on interventions that the other party considers inappropriate.

Other chapters discuss related issues. Chapter 4 analyzes patient refusals that are not in their best interests. Chapter 13 covers decisions by surrogates that are contrary to the patient's wishes or best interests. Chapter 9 discusses demands by patients or surrogates for "futile" interventions.

PATIENT OR SURROGATE INSISTENCE ON LIFE-SUSTAINING INTERVENTIONS

CLINICAL CONSIDERATIONS

Physicians are exhorted to improve palliative care near the end of life and help patients achieve a peaceful death (4-6). In some cases, however, patients or surrogates insist on life-sustaining interventions that physicians believe cause suffering (5,6).

CASE 14.1 Desire for CPR and mechanical ventilation in end-stage lung disease.

Mr. H was a 29-year-old man with end-stage cystic fibrosis who was admitted to the hospital for antibiotics and respiratory therapy. He was emaciated, required home oxygen, and was dyspneic walking around his home. During conversations he often paused to catch his breath or to cough up thick secretions. Lung transplantation was not an option for him because of recurrent aspiration pneumonia. Mr. H understood that his shortness of breath would get worse. He appreciated that physicians believed that cardiopulmonary resuscitation (CPR) or mechanical ventilation had very little chance of success. He further realized that the physicians believed that if he required intubation and mechanical ventilation, he could not be weaned off the ventilator. He responded, "My entire life has been a struggle. No one thought I would live this long. I've always beaten the odds. I've always been a fighter. I'll keep fighting until the man upstairs tells me it's time to stop."

Mr. H rejected a palliative approach and was willing to accept odds that physicians believed were unacceptable. His core values included overcoming situations that others believed were hopeless. Other patients also want life-sustaining interventions that offer a very small hope of success.

The SUPPORT study documented shortcomings in palliative care at the end of life. This study enrolled over 9,000 hospitalized patients with an advanced stage of one of nine illnesses (4). These patients had a hospital mortality of more than 25% and a 6-month mortality of almost 50%. In the latter phase of this project, research nurses gave physicians computer-generated prognoses for each

patient and documented patients' and families' preferences for treatment. For many patients who died, their last days included "undesirable states": 38% spent at least 10 days in an ICU, 46% received mechanical ventilation within 3 days of death, and 45% were unconscious during their last 3 days of life (4,7). Relatives reported that 50% of conscious dying patients experienced moderate or severe pain during their last 3 days of life. These findings were widely interpreted as evidence of inappropriately aggressive use of technology and failure to relieve suffering near the end of life (4-6).

The SUPPORT study also showed that many seriously ill patients desire interventions that have a low likelihood of success. One paper analyzed patients with metastatic cancer whose physicians predicted a 6-month survival of 10%. Thirty-six percent of such patients preferred life-extending therapy rather than relief from pain and discomfort as the primary goal of care (8). Among those patients who believed that they had a 90% chance or better of surviving for 6 months, 61% wanted life-extending therapy, compared to only 15% of patients who estimated their chance for surviving 6 months to be less than 90%.

ETHICAL CONSIDERATIONS

The ethical guideline of beneficence requires physicians to oppose requests for interventions that would not improve outcomes but would cause serious suffering. In this section we analyze three particularly difficult situations: requests that "everything" be done, requests for interventions based on religious beliefs, and requests for interventions that cause suffering with little prospect of medical benefit.

CASE 14.2 Family insistence that everything be done (9).

Bishop P is a 60-year-old African-American man with diabetes, quadriplegia, and persistent infections. One year ago he developed Staphylococcus aureus meningitis, epidural abscess, and pneumonia. During his hospitalization Bishop P developed quadriplegia, respiratory failure, renal failure, and persistent fevers.

Ten months later, Bishop P was rehospitalized with urosepsis from Enterobacter cloacae. Hypotension, respiratory failure, renal failure, stroke, and seizures complicated his course. He required mechanical ventilation and dialysis. Despite multiple courses of antibiotics, his blood cultures remained positive for E. cloacae, resistant to all antibiotics. A drug reaction caused a total body rash, and his skin sheared away around his bandages and electrocardiographic leads. The physicians believed that further interventions would be inhumane and disfiguring, that he would not survive the hospitalization, and that attempts at CPR would be futile.

Bishop P's Pentecostalist church emphasizes faith healing. Bishop P was obtunded and could not state his preferences for care. His family insisted that everything be done because he believed that all life was sacred.

Bishop P's family wanted to act in accordance with his lifelong values. Such substituted judgments by surrogates are a legitimate basis for decisions when patients lack decision-making capacity and have not given clear advance directives (see Chapter 12).

REQUESTS THAT "EVERYTHING" BE DONE

In Case 14.2 the family requested that "everything" be done. The physicians should first clarify what they mean by "everything." Many patients or surrogates do not want literally everything done and acknowledge that in some situations interventions might be far more likely to cause suffering or harm than benefit. It is also useful to elicit the values and concerns that animate such requests. Some patients or surrogates might be concerned that if they do not insist on interventions, beneficial treatments will be withheld. Such concerns can be addressed directly.

RELIGION-BASED INSISTENCE ON INTERVENTIONS

As in Case 14.2, many patients base decisions about life-sustaining interventions on their religious or spiritual beliefs (10,11). Religion-based reasons deserve special respect because they reflect a person's core values and identity (9). These beliefs might lead some patients to insist on interventions.